# Population size estimate of people with high-risk opioid use and an exploration of people with high-risk use of crack cocaine and other drugs in the Netherlands

## OPAAK project

## Final report

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June 2025

This research was conducted under the project leadership of the Trimbos Institute and in collaboration with the Mainline Foundation.
The project was funded by the Dutch Ministry of Health, Welfare and Sport (subsidy number 333345). The funder had no role in the design, data collection, analysis, or reporting of this study.

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The final report of the OPAAK project is the result of a collaborative effort between the Trimbos Institute (Ti) and the Mainline Foundation (Mainline).

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Guus Cruts and Margriet van Laar (Ti) provided expert guidance on the study's subject matter, assisted in the interpretation and contextualization of key findings, and contributed to the final report.

Thomas Martinelli and Daan van der Gouwe (Ti) carried out the needs assessment (Chapter 4). They performed focus groups and interviews, analysed the data, and wrote the report.

Lisa Strada (Ti), project leader of OPAAK, managed and coordinated all aspects of the project. She supervised the data analysis and served as primary author of Chapters 1, 2, and 3, and the final report. She also facilitated discussions on the interpretation of findings with the project team, external experts, and the advisory board.

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# Preface

Substance use continues to pose significant challenges to public health, with evolving patterns and emerging risks requiring constant vigilance and adaptation. While the long-standing focus in the Netherlands has been on high-risk opioid use, there is increasing recognition of other vulnerable populations, such as those with high-risk use of crack cocaine, as well as new groups of people exhibiting high-risk use of other drugs. Critical gaps remain in our understanding of these populations, their needs, and the adequacy of services designed to support them.

The OPAAK study was conceived to address these gaps, building on the strong tradition of harm reduction and evidence-based policymaking in the Netherlands. By employing a comprehensive research design, this study provides updated population size estimates for people with high-risk use of opioids and crack cocaine, evaluates the coverage and quality of essential services like opioid agonist therapy and needle and syringe programs, and identifies new emerging groups of people with high-risk drug use.

As public health priorities evolve, so too must our approaches to care, ensuring they remain grounded in evidence, equity, and compassion. This report serves as a benchmark and a call to action, emphasizing the need for continued investment in monitoring and the co-creation of solutions with affected communities.

This research was funded by the Dutch Ministry of Health, Welfare and Sport. The funder had no role in the study's design, data collection, analysis, or reporting of findings. This independence ensured that our work remained objective, unbiased, and focused solely on advancing the knowledge in this field.

We extend our deepest gratitude to the advisory board of the OPAAK study for their comprehensive and invaluable contributions. Their expertise and thoughtful guidance have been instrumental in enriching the quality of this research. The advisory board was composed of the following members:

Peter Blanken, PhD, Senior researcher, Parnassia Addiction Research Centre, Brijder Addiction Treatment

Jeroen Wisselink, Program manager and Senior researcher, Stichting Informatievoorziening Zorg

Marcel Buster, PhD, Senior researcher, GGD Amsterdam

We hope this report will serve as a valuable resource for policymakers, researchers, and healthcare professionals, contributing to a more equitable and informed approach to addiction care in the Netherlands.

Lisa Strada, PhD
Trimbos Institute

# Summary


## Rationale

High-risk drug use refers to recurrent drug use that is causing actual harms to a person or is placing the person at high risk of suffering harms. In the Netherlands, the last population size estimate of people with high-risk opioid use (HROU) was performed in 2012. The last exploration of people with high-risk crack cocaine use without high-risk opioid use (HRCCU-only) was carried out in 2008. Current data on the health and wellbeing of these populations and whether services still meet their needs is lacking. Additionally, data on the coverage of opioid agonist therapy and needle and syringe programs in the Netherlands is outdated or missing, and can therefore no longer be reported (inter)nationally. Various signs also point to the emergence of new groups of people with high-risk drug use. Monitoring these developments is essential for addressing potential threats to public health.

## Aims

The OPAAK study aimed to provide up-to-date information on the populations of people with high-risk use of opioids and crack cocaine, while also identifying emerging groups of people with high-risk drug use. The study was structured into four main goals. First, we aimed to estimate the population sizes of people with HROU and HRCCU-only and assess their drug use patterns, health, wellbeing, and integration in addiction care services. To contextualize and assist with the interpretation of the population size estimates, we evaluated the accuracy of LADIS, the national registration system of addiction care in the Netherlands. Second, we assessed the coverages of opioid agonist therapy and needle and syringe programs to evaluate access to these essential healthcare services. Third, we performed a needs assessment of people with HROU and HRCCU-only to better understand their specific challenges and needs. Fourth, we aimed to identify and characterize new emerging groups of people with high-risk drug use. With this comprehensive approach of the OPAAK study, we sought to address both established and evolving aspects of high-risk drug use in the Netherlands.

## Study design

OPAAK was an observational, cross-sectional study utilizing both quantitative and qualitative research methods. Data for the population size estimates and service coverages was collected from people with HROU and HRCCU-only by means of structured interviews, in which participants completed a questionnaire together with field workers. Participants were recruited in eight cities across the Netherlands between July 2023 and July 2024. The population size estimates were calculated using the Multiplier Method. For the needs assessment, focus groups and individual interviews were conducted with people with HROU and HRCCU-only in different cities in the Netherlands. Finally, to identify new emerging groups of people with high-risk drug use, focus groups and individual interviews were organized with a range of professionals and other experts across the Netherlands.

## Study population

The overall study population was adults (age 18 or older) self-reporting high-risk drug use. The two main target groups were people with high-risk opioid use (HROU), who may or may not also engage in high-risk crack cocaine use, and people with high-risk crack cocaine use without high-risk opioid use (HRCCU-only). Eligibility criteria were based on the case definitions of high-risk drug use of the European Union Drugs Agency.

## Findings

### Chapter 1. Challenges with the registration of addiction care: an assessment of the coverage of LADIS and implications for the OPAAK study

To estimate the population sizes, data from LADIS - the national addiction care registry in the Netherland – is needed. Because the accuracy of LADIS directly influences the reliability of population size estimates (see Chapter 2: Methods), the research began with an evaluation of the completeness and accuracy of LADIS-data.

This analysis revealed significant challenges in the registration of addiction care that compromise both the reliability of population size estimates and our broader understanding of addiction care services. LADIS lacks transparency and granularity. For instance, data is linked to addiction care institutes rather than specific service locations, making it difficult to assess data completeness. The definition of ‘addiction care’ is

ambiguous, resulting in some institutes opting out of LADIS reporting. This leads to inconsistent reporting of services, such as drug consumption rooms and assisted living facilities. The incomplete registration of opioid agonist therapy further exacerbates the issue of underreporting. Additionally, inconsistent and incomplete data entry at service locations compromises data quality. This problem is partly driven by the widespread registration burden on staff, as well as their growing resistance to reporting data due to inefficient IT systems. Another critical shortcoming is that certain drugs are not registered accurately in the system. For example, some clients are labelled as 'cocaine unspecified' because staff did not specify whether the individual uses powdered cocaine or crack cocaine. We also highlight a number of other care-related issues, such as that drug consumption rooms are often limited to people who are already clients at an addiction care institute, rather than being low-threshold services open to any people who use drugs. To enhance the accuracy of LADIS data it is vital to enforce mandatory reporting, apply consistent reporting standards, provide user-friendly IT systems, and allocate more resources to addiction care staff and the IVZ Foundation to reduce the registration burden and support quality assurance efforts.

**Chapter 2. Population size estimates and characteristics of people with HROU and HRCCU-only**

The main goal of this study was to estimate the size and characteristics of two populations: people with high-risk opioid use (HROU), who may or may not also use crack cocaine, and people with high-risk crack cocaine use without high-risk opioid use (HRCCU-only). To perform the population size estimates (PSEs), we employed the Multiplier Method, which relies on two key components: a benchmark sourced from an existing database and a multiplier obtained from a field study. The benchmark was derived from the LADIS database, while the multiplier was derived from data collected through structured interviews with 393 HROU individuals and 127 HRCCU-only individuals.

Findings must be interpreted with caution, as key assumptions of the Multiplier Method were not fully met. This is due to critical gaps in the registration of addiction care (see Chapter 1) as well as challenges in the recruitment, which may have introduced bias into the sample. Additionally, methodological limitations prevent a direct comparison with previous PSEs. With these caveats in mind, we calculated the PSEs. The estimated size of the HROU population in 2023 was 13,300 (95% CI: 12,600 – 14,200), slightly smaller than the 2012 estimate of 14,300 (13,400 – 16,300). However, overlapping confidence intervals suggest that this difference may not be statistically significant. In contrast, the 2023 HRCCU-only estimate was 16,000 (95% CI: 11,300 – 25,200), larger than the 2008 estimate of 12,400 (10,300 – 15,600). However, this estimate is based on a pilot study with a small sample size and should be regarded as preliminary and of limited reliability. Field workers reported identifying more HRCCU-only individuals compared to HROU individuals during recruitment. This is not reflected in the results due to the predefined sample size limits, but it may have affected the PSEs. It also shows that the HRCCU-only population is easy to reach, in contrast to the last study in 2008 when HRCCU-only individuals were hard to reach. Finally, it is also important to highlight that the HRCCU-only estimate excludes 'dual users' who engage in high-risk use of both opioids and crack cocaine. The total population of people with high-risk crack cocaine use (HRCCU, with and without opioid use) is estimated to be approximately 27,900.

Access to addiction care appears to be lower for both groups compared to 15 years ago. In 2023, 61% of HROU individuals received LADIS-registered addiction care, compared to 87% in 2008. Among HRCCU-only individuals, the in-LADIS rate was even lower: 31% in 2023, compared to 41% in 2008. It is uncertain whether the lower in-LADIS rates reflect a true decline in access to care or whether they are influenced by other factors. Identifying the underlying cause is crucial, as inaccuracies in the in-LADIS rates may impact the PSEs. Potential contributing factors and comparisons with broader trends in the field are explored in the discussion.

Descriptive characteristics reveal important differences between the two groups. HRCCU-only individuals were generally younger, more often born outside of Europe, made less use of addiction care services and drug consumption rooms, and were more likely to reside in homeless shelters and night shelters than HROU individuals. Moreover, a significant proportion of the HRCCU-only group reported no history of opioid use, suggesting that this group largely represent a new population that did not transition from opioids to crack cocaine. Despite these distinctions, there were also similarities between the groups. High-risk crack cocaine use was not only reported by HRCCU-only individuals, but also the vast majority of HROU participants (89.3%), with most using it near-daily (on 23 of the past 30 days). In both groups, around three-quarter of participants demonstrated significant mental and physical health needs, yet mental health services were underutilized (16%). Past-year injection drug use was low among HROU participants (12%), and needle sharing was rare (2% among past-year injection drug users), yet past-year sharing of drug paraphernalia other than needles, such as

crack pipes, was prevalent (63.8% HROU, 66.4% HRCCU-only). Furthermore, HIV and HCV testing rates were low among people who inject drugs, indicating critical gaps in adherence to screening recommendations. Finally, individuals born outside the Netherlands were less in addiction care and opioid agonist therapy than those born in the Netherlands.

### Chapter 3. Coverage of opioid agonist therapy and needle and syringe programs

Opioid agonist therapy (OAT) and needle and syringe programs (NSP) are essential harm reduction strategies for managing opioid dependence and preventing blood-borne infections. OAT coverage represents the proportion of individuals with HROU receiving treatment with medications such as methadone. Based on fieldwork data, OAT coverage was estimated at 59.8%, revealing a considerable treatment gap. Moreover, the OAT coverage is lower than in 2012 when it was approximately 80%. However, a direct comparison should be approached with caution due to potential biases in the field samples (see Chapter 2) and possible changes in service delivery (see the Discussion).

NSP coverage measures the availability of sterile syringes for people who inject drugs. Although injection drug use is relatively low (about 12% among HROU, see Chapter 2), maintaining good NSP coverage is vital to protect public health. NSP coverage was evaluated on a case-by-case basis by dividing the number of clean syringes available per week by injection frequency per week. Among 28 respondents, the median NSP coverage was 169%, meaning participants typically had approximately 1.7 clean syringes available per injection. This exceeds the World Health Organization's target of 82%. While this finding is promising, it is based on a small sample size and focuses only on the traditional population of people who inject drugs, which mainly consists of opioid users. Emerging groups, such as people in the chemsex community who inject drugs, were not included. However, the high NSP coverage appears credible, as only one participant in the representative field sample reported past-year needle-sharing (see Chapter 2). Future research may explore existing barriers to OAT and broaden NSP assessments to encompass all groups who inject drugs.

### Chapter 4. Needs assessment of people with HROU and HRCCU-only

A needs assessment was conducted through focus groups and individual interviews with 27 HROU individuals and 13 HRCCU-only individuals. The findings were organized around three central questions: What are clients' perspectives on the care and services currently available? What changes would they make to existing care and services? And what additional services do they believe are needed?

Participants shared a range of positive and negative experiences with the current care system. While many felt their needs were met, others raised concerns about long waiting lists, lack of privacy, and inconsistent care due to frequent staff turnover. Many participants expressed a desire for more respectful treatment and a less judgmental approach from providers. They also emphasized the need for proactive outreach for people with high-risk drug use who may struggle to articulate their needs, as well as the importance of more safe consumption spaces. Furthermore, participants highlighted a gap in services for older users who want ongoing support that focuses on quality of life rather than solely on cessation or reduction of drug use. Specific to crack cocaine use, they noted a lack of specialized treatment and harm reduction services. Discussions included the potential benefits and drawbacks of agonist pharmacotherapy for crack cocaine, with participants emphasizing the need for approaches that address the psychological aspects of dependence, rather than focusing exclusively on physical dependence. Social factors such as homelessness were identified as significant barriers to accessing and benefiting from treatment. Recommendations for improving care include increasing outreach efforts, adopting a more personalized and nonjudgmental approach to care, and enhancing services tailored specifically for people using crack cocaine.

### Chapter 5. New trends and groups of people with high-risk drug use

To explore emerging trends and groups of people with high-risk drug use, two focus groups and twelve individual interviews were conducted with professionals and field workers. It is important to emphasize that these findings are based on field observations and subjective impressions rather than quantitative data. The analysis identified nine key trends and groups that grew in the past 5 years, each presenting unique challenges:

(1) The use of non-prescribed psychopharmaceuticals appears to have increased in recent years, with synthetic opioids, benzodiazepines, and other sedatives raising significant concerns. These substances are often sold in

unlabelled packaging, heightening the risk of misuse and overdose. (2) The Chemsex community is growing, both within and beyond the traditional MSM (men who have sex with men) population. Drug taking practices are changing, with substances like 3-MMC being increasingly used, particularly among injecting Chemsex users, leading to serious health complications. (3) Many Eastern European migrants and undocumented individuals use heroin, crack cocaine, alcohol, and speed. However, they face significant legal and bureaucratic barriers to accessing addiction care and healthcare. (4) Unaccompanied (formerly) underaged asylum seekers are disproportionally using medications like Rivotril (a benzodiazepine) and Lyrica (an anticonvulsant and neuropathic pain agent). These are often prescribed without adequate oversight or support. (5) Some expats experience a rapid escalation from recreational to problematic drug use, but struggle to get help due to cultural barriers and limited access to healthcare in languages other than Dutch. (6) The online availability of new psychoactive substances (NPS), such as 3-MMC and Alpha-PVP/PHP, has contributed to increased use, often in private settings, complicating efforts to identify and address problematic use. (7) Young people, especially those aging out of youth care or experiencing homelessness, are increasingly turning to substances such as crack cocaine and 3-MMC. (8) Psychedelics are being used more frequently by individuals with mental health issues as a form of self-medication. (9) Individuals transitioning out of detention often lack adequate support, leading to a heightened risk of overdose and treatment interruption. Recommendations for research priorities are proposed.

## Discussion and conclusions

Reliable estimates of population size and care coverage are essential for effective public health planning and resource allocation. Equally important is the evaluation of how well existing services meet the needs of clients, as this impacts the effectiveness of care. In the Netherlands, most drug-related services and policies were developed over two decades ago and have not undergone systematic evaluation from a patient-centred perspective. The OPAAK study addresses this gap by providing critical insights into the current state of high-risk drug use and relevant services in the country.

Interpretation of population size estimates and broader trends

The study findings indicate that, in 2023, the population of people with high-risk opioid use (HROU) seems slightly smaller than in 2012, while the population of people with high-risk crack cocaine use and without high-risk opioid use (HRCCU-only) appears larger than in 2008. Findings need to be interpreted with caution, as key assumptions of the Multiplier Method were not fully met, and methodological limitations prevent direct comparisons with previous population size estimates (PSEs). The estimated population sizes are not reliable, especially due to the poor registration of addiction care in LADIS.

The PSEs may be influenced by changes in access to addiction care. Findings from the OPAAK study indicate that access to care appears lower compared to a decade ago. Similarly, the Trimbos institute's 'Synthetic Opioid Preparedness Scan' reported a growing number of drug users who are not utilizing addiction care services. This raises the question whether the same population is accessing addiction care less or if other factors contribute to this apparent decline. One notable factor is the growing number of individuals born outside the Netherlands, who, according to our data, are accessing addiction care less than those born in the Netherlands. If specific groups face greater challenges in accessing care, this could result in an overestimation of PSEs. Experts have also observed that an increasing number of patients is receiving opioid agonist therapy through general practitioners. As not all general practitioners report to LADIS, this may lower the in-LADIS rate, thereby overestimating the HROU population. Moreover, specialized addiction care services for crack cocaine users remain limited, which may explain the particularly low percentage of HRCCU-only individuals in care.

Despite these uncertainties in the data, the findings align with broader observed trends. The small decline in the HROU population mirrors the slow decrease in HROU patients in LADIS. It is important to note that underreporting to LADIS (see Chapter 1) likely amplifies the apparent decline in HROU patients, while the shift in OAT delivery to general practitioners may have lowered the in-LADIS rate, artificially inflating the HROU PSE. Considering these factors, the actual decline in the HROU population likely lies somewhere between the decreasing trends indicated by the PSE and addiction care data. The increase in the HRCCU-only population aligns with the growing prevalence of crack cocaine use observed by field workers and reported in other European countries. Moreover, nearly all participants in the OPAAK study reported high-risk crack cocaine use, including nearly 90% of HROU individuals. This demonstrates that the prevalence of crack cocaine use is high and that crack cocaine currently plays a bigger role than opioids in these populations.

Increasing use of crack cocaine

Given the increase in crack cocaine use across Europe, it seems plausible that a similar trend may be emerging in the Netherlands. The raises an important question: how should health care providers and policy makers respond to a rise in crack cocaine use? The difficulty is that there is no established pharmaceutical treatment to curb addiction in the same way that opioid agonist therapy is prescribed to people who use opioids. Other countries that have been dealing with crack epidemics, such as Switzerland, propose that drug consumption rooms (DCRs) may be a key tool to dealing with a crack epidemic and reduce associated harms and nuisance. Switzerland has expanded the DCR model to also include additional supportive services, such as rest areas and hygiene facilities. In the present study, individuals in the HRCCU-only group exhibited low use of DCRs and high rates of drug paraphernalia sharing, underscoring the need to reassess and adapt current DCR policies in the Netherlands to improve access for people who use crack cocaine. Also the needs assessment demonstrated that people who use crack cocaine want more specialized care and support services. Reports from other European countries indicate that the crack cocaine scene has become increasingly antisocial and violent. As regular use of crack cocaine use is expensive, many turn to procurement crime to sustain their dependence. While there are no widespread reports of antisocial behaviour in the Netherlands yet, this may only be a matter of time.

Recommendations for policies and interventions

This study underscores the need for tailored, equitable, and inclusive addiction care policies and interventions. Particular attention is needed to address disparities in addiction care for the HRCCU-only group, the aging HROU population, and individuals not born in the Netherlands. The high, and potentially increasing, prevalence of crack cocaine use highlights the urgency of developing specialized treatment and harm reduction services for this group. Experts believe that crack cocaine use will continue to rise in Europe, which underscores the importance of enhancing 'preparedness' for associated public health and safety risks. Targeted outreach efforts are critical to connect non-Dutch individuals and other hard-to-reach individuals with vital services, including drug consumption rooms and HIV/HCV testing. Furthermore, gaining a deeper understanding of the evolving needs of the aging population of people who use opioids is key to adapting services effectively where needed. Finally, improving the registration and quality of addiction care data in LADIS is crucial, as reliable data is essential for accurate insights into addiction care and developing evidence-based policies.

# Samenvatting

## Achtergrond

Hoogrisico-drugsgebruik verwijst naar herhaaldelijk drugsgebruik dat daadwerkelijk schade veroorzaakt voor een persoon of deze persoon blootstelt aan een hoog risico op schade. In Nederland werd de laatste populatieschatting van mensen met hoogrisico-opioïdengebruik (HROU) uitgevoerd in 2012. De laatste verkenning van mensen met hoogrisico-crackcocaïnegebruik zonder hoogrisico-opioïdengebruik (HRCCU-only) dateert uit 2008. Er ontbreekt actuele informatie over de gezondheid en het welzijn van deze populaties. Bovendien is het de vraag of de huidige diensten nog aansluiten bij hun behoeften. Daarnaast zijn gegevens over de dekking van opiaten onderhoudsbehandeling en spuitenruilprogramma's in Nederland verouderd of ontbreken, waardoor rapportage (inter)nationaal niet langer mogelijk is. Er zijn ook aanwijzingen voor de opkomst van nieuwe groepen mensen met hoogrisico-druggebruik. Monitoring van deze ontwikkelingen is essentieel om potentiële bedreigingen voor de volksgezondheid aan te pakken.

## Doelstellingen

Het doel van de OPAAK-studie was om actuele informatie te verschaffen over de populaties mensen met hoogrisico-opioïdengebruik en hoogrisico-crackcocaïnegebruik, evenals het identificeren van opkomende groepen mensen met hoogrisico-drugsgebruik. De studie was opgebouwd rond vier hoofddoelen: Ten eerste wilden we de populatieomvang van mensen met HROU en HRCCU-only schatten en hun drugsgebruikspatronen, gezondheid, welzijn en integratie in de verslavingszorg in kaart brengen. Om de populatieschattingen te contextualiseren en beter te interpreteren, hebben we de nauwkeurigheid van LADIS – het landelijke registratiesysteem voor verslavingszorg in Nederland – geëvalueerd. Ten tweede beoordeelden we de dekkingsgraden van opiaten onderhoudsbehandeling en spuitenruilprogramma's om toegang tot deze essentiële gezondheidszorgdiensten te evalueren. Ten derde voerden we een behoefteanalyse uit onder mensen met HROU en HRCCU-only om hun specifieke uitdagingen en behoeften beter te begrijpen. Ten vierde wilden we opkomende trends en groepen mensen met hoogrisico-drugsgebruik identificeren en karakteriseren. Met deze uitgebreide aanpak van de OPAAK-studie wilden we zowel bestaande als opkomende aspecten van hoogrisico-drugsgebruik in Nederland aanpakken.

## Onderzoeksopzet

OPAAK was een observationele, cross-sectionele studie waarin zowel kwantitatieve als kwalitatieve onderzoeksmethoden werden toegepast. Gegevens voor de populatieschattingen en dekkingen van diensten werden verzameld via gestructureerde interviews, waarbij deelnemers met veldwerkers een vragenlijst invulden. Deelnemers werden geworven in acht Nederlandse steden tussen juli 2023 en juli 2024. De populatieschattingen werden berekend met de Multiplier Method. Voor de behoefteanalyse werden focusgroepen en individuele interviews gehouden. Nieuwe opkomende trends en groepen gebruikers werden geïdentificeerd via focusgroepen in individuele interviews met verschillende professionals en andere experts in heel Nederland.

## Studiepopulatie

De studiepopulatie bestond uit volwassenen (18 jaar of ouder) die hoogrisico-drugsgebruik rapporteerden. De twee belangrijkste doelgroepen waren mensen met hoogrisico-opioïdengebruik (HROU), die al dan niet ook crackcocaïne gebruiken, en mensen met hoogrisico-crackcocaïnegebruik zonder hoogrisico-opioïdengebruik (HRCCU-only). De inclusiecriteria waren gebaseerd op de casusdefinities van hoogrisico-drugsgebruik van de European Union Drugs Agency.

## Bevindingen

### Hoofdstuk 1. Uitdagingen bij de registratie van verslavingszorg: een beoordeling van de dekking van LADIS en de implicaties voor de OPAAK-studie

Om de omvang van de populaties te schatten, zijn gegevens uit het LADIS – het landelijke register voor verslavingszorg in Nederland – nodig. Omdat de nauwkeurigheid van LADIS essentieel is voor een betrouwbare populatieschatting (zie Hoofdstuk 2: Methodiek), begon het onderzoek met een evaluatie van de volledigheid en nauwkeurigheid van de LADIS-gegevens.

Deze analyse bracht aanzienlijke uitdagingen bij de registratie van verslavingszorg aan het licht, die zowel de betrouwbaarheid van populatieschattingen als het bredere begrip van verslavingszorgdiensten aantasten. LADIS mist transparantie en gedetailleerdheid. Zo worden gegevens gekoppeld aan verslavingszorginstellingen in plaats van aan specifieke locaties, waardoor het moeilijk is om de volledigheid van gegevens te beoordelen. De definitie van 'verslavingszorg' is onduidelijk, waardoor sommige instellingen ervoor kiezen om niet aan LADIS te rapporteren. Dit leidt tot inconsistente rapportage van diensten zoals gebruikersruimtes en begeleid wonen. De onvolledige registratie van opiaten onderhoudsbehandeling verergert het probleem van onderrapportage. Daarnaast leidt inconsistente en onvolledige gegevensinvoer op locatieniveau tot een verminderde datakwaliteit. Dit probleem wordt deels veroorzaakt door de hoge registratielast bij personeel, als ook hun toenemende weerstand om gegevens in te voeren vanwege inefficiënte en gebruikersonvriendelijke IT-systemen. Een andere belangrijke tekortkoming is dat bepaalde drugs niet nauwkeurig in het systeem worden geregistreerd. Sommige cliënten worden bijvoorbeeld gecategoriseerd als ‘cocaïne niet-gespecificeerd', omdat medewerkers niet hebben aangegeven of de cliënten poeder- of crackcocaïne gebruikten. Daarnaast signaleren wij nog een paar knelpunten in de zorg, bijvoorbeeld dat gebruikersruimten vaak alleen toegankelijk zijn voor mensen die al cliënt zijn bij een verslavingszorginstelling, in plaats van laagdrempelige voorzieningen te zijn die openstaan voor iedereen die drugs gebruikt. Om de nauwkeurigheid van LADIS-gegevens te verbeteren, is het essentieel om verplichte rapportage te handhaven, consistente rapportagestandaarden toe te passen, gebruiksvriendelijke IT-systemen te bieden, en meer middelen toe te wijzen aan medewerkers van de verslavingszorg en Stichting IVZ om de registratielast te verminderen en de kwaliteitsborging te ondersteunen.

### Hoofdstuk 2. Populatieomvang en kenmerken van mensen met HROU en alleen HRCCU

Het hoofddoel van deze studie was om de omvang en kenmerken te schatten van twee populaties: mensen met hoogrisico-opioïdengebruik (HROU), die al dan niet ook crackcocaïne gebruiken, en mensen met hoogrisico-crackcocaïnegebruik zonder hoogrisico-opioïdengebruik (HRCCU-only). Om de populatieomvang te schatten, hebben we de Multiplier Methode toegepast, die gebaseerd is op twee belangrijke componenten: een benchmark afkomstig uit een bestaande database en een multiplier verkregen uit een veldstudie. De benchmark werd afgeleid van de LADIS-database, terwijl de multiplier werd afgeleid uit gegevens verzameld via gestructureerde interviews met 393 HROU-individuen en 127 HRCCU-only-individuen.

De resultaten moeten voorzichtig worden geïnterpreteerd, omdat niet aan alle aannames van de Multiplier Method is voldaan. Dit komt door kritieke lacunes in de registratie van verslavingszorg (zie Hoofdstuk 1) en uitdagingen bij de werving, die mogelijk voor vertekening in de steekproef hebben gezorgd. Daarnaast verhinderen methodologische beperkingen een directe vergelijking met eerdere schattingen van de populatieomvang. Met deze kanttekeningen in gedachten hebben we de schattingen berekend. De omvang van de HROU-populatie in 2023 werd geschat op 13.300 (95% BI: 12.600 – 14.200), iets kleiner dan de schatting uit 2012 van 14.300 (13.400 – 16.300). Overlappende betrouwbaarheidsintervallen suggereren echter dat dit verschil mogelijk niet statistisch significant is. Daarentegen werd de HRCCU-only-populatie in 2023 geschat op 16.000 (95% BI: 11.300 – 25.200), groter dan de schatting uit 2008 van 12.400 (10.300 – 15.600). Deze schatting is echter gebaseerd op een pilotstudie met een kleine steekproef en moet als voorlopig en van beperkte betrouwbaarheid worden beschouwd. Veldwerkers rapporteerden dat ze tijdens de werving meer individuen met HRCCU-only tegenkwamen in vergelijking met HROU-individuen. Dit komt niet tot uiting in de resultaten vanwege de vooraf vastgestelde steekproeflimieten, maar kan wel van invloed zijn geweest op de geschatte populatieomvang. Het toont ook aan dat de HRCCU-only populatie gemakkelijk bereikbaar is, in tegenstelling tot de laatste studie in 2008, toen HRCCU-only individuen moeilijk te bereiken waren. Tot slot is het belangrijk te benadrukken dat de HRCCU-only schatting geen personen omvat die zowel opioïden als crackcocaïne risicovol gebruiken. De totale populatie van mensen met hoogrisico-crackcocaïnegebruik (HRCCU, met en zonder gebruik van opioïden) wordt geschat op ongeveer 27.900.

De toegang tot verslavingszorg lijkt voor beide groepen lager te liggen dan 15 jaar geleden. In 2023 ontving 61% van de HROU-individuen LADIS-geregistreerde zorg, vergeleken met 87% in 2008. Onder HRCCU-only-individuen was het percentage nog lager: 31% in 2023, ten opzichte van 41% in 2008. Het is onduidelijk of de lagere in-LADIS ratio een werkelijke afname in de toegang tot zorg weerspiegelt of dat andere factoren hierop van invloed zijn. Het achterhalen van de onderliggende oorzaak is essentieel, aangezien onnauwkeurigheden in de in-LADIS ratio’s invloed kunnen hebben op de schatting van de populatieomvang. Mogelijk bijdragende factoren en vergelijkingen met bredere trends in het veld worden besproken in de discussie.

Descriptieve kenmerken tonen belangrijke verschillen tussen de twee groepen. HRCCU-only-individuen waren over het algemeen jonger, vaker geboren buiten Europa, maakten minder gebruik van verslavingszorg en gebruikersruimtes, en verbleven vaker in daklozen- en nachtopvang dan HROU-individuen. Bovendien gaf een aanzienlijk deel van de HRCCU-only groep aan geen geschiedenis van opioïdengebruik te hebben, wat suggereert dat deze groep grotendeels een nieuwe populatie is die niet is overgestapt van opioïden naar crackcocaïne. Ondanks deze verschillen waren er ook overeenkomsten tussen de groepen. Hoogrisico-gebruik van crackcocaïne werd zowel door HRCCU-only individuen als door de overgrote meerderheid HROU-deelnemers (89.3%) gemeld, waarbij de meesten het bijna dagelijks gebruikten (op 23 van de afgelopen 30 dagen). Beide groepen vertoonden aanzienlijke mentale en fysieke gezondheidsbehoeften, maar maakten weinig gebruik van geestelijke gezondheidszorg. Het injecterend drugsgebruik in het afgelopen jaar was laag onder HROU-deelnemers (12%), en het delen van naalden kwam zelden voor (2% onder injecterende gebruikers). Echter, het delen van andere druggerelateerde attributen, zoals crackpijpen, in het afgelopen jaar was wijdverbreid (63,8% HROU, 66,4% HRCCU-only). Daarnaast waren de HIV- en HCV-testpercentages laag onder mensen die drugs injecteren, wat wijst op aanzienlijke tekortkomingen in het naleven van screeningsaanbevelingen. Ten slotte waren personen die buiten Nederland geboren zijn minder vaak in verslavingszorg en opiaten onderhoudsbehandeling dan degenen die in Nederland geboren zijn.

### Hoofdstuk 3. Dekking van opiaten onderhoudsbehandeling en spuitenruilprogramma's

Opiaten onderhoudsbehandeling (ook wel opioïden agonist therapie genoemd, OAT) en spuitenruilprogramma's (NSP) zijn essentiële schadebeperking strategieën voor het beheersen van opioïdenafhankelijkheid en het voorkomen van bloed overdraagbare infecties. De OAT-dekking vertegenwoordigt het percentage HROU-individuen dat wordt behandeld met medicatie zoals methadon. Op basis van gegevens uit het veldwerkonderzoek werd de OAT-dekking geschat op 59,8%, wat wijst op een aanzienlijke behandelingskloof. Bovendien ligt de OAT-dekking lager dan in 2012, toen deze ongeveer 80% bedroeg. Een directe vergelijking moet echter voorzichtig worden benaderd vanwege mogelijke vertekeningen in de veldsteekproeven (zie Hoofdstuk 2) en mogelijke veranderingen in de hulpverlening (zie de Discussie).

De NSP-dekking meet de beschikbaarheid van steriele spuiten voor mensen die drugs injecteren. Hoewel het injecterend drugsgebruik relatief laag is (ongeveer 12% HROU, zie Hoofdstuk 2), is het behouden van een goede NSP-dekking cruciaal voor de volksgezondheid. De NSP-dekking werd per geval beoordeeld door het aantal beschikbare schone spuiten per week te delen door de injectiefrequentie per week. Onder 28 respondenten was de mediane NSP-dekking 169%, wat betekent dat deelnemers doorgaans ongeveer 1,7 schone spuiten per injectie beschikbaar hadden. Dit overtreft de doelstelling van 82% die is vastgesteld door de Wereldgezondheidsorganisatie (WHO). Hoewel deze bevinding veelbelovend is, is deze gebaseerd op een kleine steekproef en richt deze zich uitsluitend op de traditionele populatie van mensen die drugs injecteren, voornamelijk opioïdengebruikers. Opkomende groepen, zoals injecterende gebruikers in de chemsex community, zijn niet meegenomen in de analyse. Echter lijkt de hoge NSP-dekking geloofwaardig, aangezien slechts één deelnemer in de representatieve veldsteekproef meldde dat hij in het afgelopen jaar naalden had gedeeld (zie Hoofdstuk 2). Toekomstig onderzoek zou bestaande barrières voor OAT kunnen verkennen en NSP-evaluaties kunnen uitbreiden naar alle groepen die drugs injecteren.

### Hoofdstuk 4. Behoefteanalyse van mensen met HROU en alleen HRCCU

Een behoefteanalyse (‘needs assessment’) werd uitgevoerd via focusgroepen en individuele interviews met 27 HROU-individuen en 13 HRCCU-only-individuen. De bevindingen werden georganiseerd rond drie centrale vragen: Wat zijn de perspectieven van cliënten op de huidige beschikbare zorg en diensten? Welke veranderingen zouden zij aanbrengen in de bestaande zorg en diensten? En welke aanvullende diensten denken zij dat nodig zijn?

Deelnemers deelden een scala aan zowel positieve als negatieve ervaringen met het huidige zorgsysteem. Hoewel velen vonden dat aan hun zorgbehoeften werden vervuld, uitten anderen zorgen over lange wachttijden, gebrek aan privacy en inconsistente zorg door frequent personeelsverloop. Veel deelnemers gaven aan behoefte te hebben aan een meer respectvolle behandeling en een minder veroordelende benadering van zorgverleners. Ze benadrukten ook de noodzaak van proactieve ‘outreach’ voor individuen die moeite hebben om hun behoeften te verwoorden, evenals het belang van extra veilige gebruiksruimtes. Daarnaast wezen deelnemers op een gebrek aan voorzieningen voor oudere gebruikers die behoefte hebben aan voortdurende ondersteuning gericht op de kwaliteit van leven, in plaats van uitsluitend op stoppen of

verminderen van drugsgebruik. Specifiek voor crackcocaïnegebruik merkten zij een tekort aan gespecialiseerde behandeling en harm reduction diensten op. Potentiële voor- en nadelen van agonisttherapie voor crackcocaïne werden besproken. Deelnemers benadrukten daarbij het belang van benaderingen die niet alleen de fysieke afhankelijkheid aanpakken, maar zich vooral richten op de psychologische afhankelijkheid. Sociale factoren, zoals dakloosheid, werden geïdentificeerd als significante belemmeringen voor toegang tot en baat hebben bij behandeling. Aanbevelingen voor het verbeteren van zorg omvatten het vergroten van outreach-inspanningen, het aannemen van een meer gepersonaliseerde en niet-veroordelende benadering van zorg, en het verbeteren van diensten die specifiek zijn afgestemd op individuen die crackcocaïne gebruiken.

### Hoofdstuk 5. Nieuwe trends en groepen mensen met hoogrisico-drugsgebruik

Om nieuwe trends en groepen mensen met hoogrisico-drugsgebruik te verkennen, zijn twee focusgroepen en twaalf individuele interviews gehouden met verschillende professionals en veldwerkers. Het is belangrijk om te benadrukken dat deze bevindingen gebaseerd zijn op observaties uit het veld en subjectieve indrukken, en niet op kwantitatieve gegevens. Uit de analyse kwamen negen belangrijke trends en groepen naar voren die de afgelopen vijf jaar zijn gegroeid, en die elk unieke uitdagingen met zich meebrengen:

(1) Het gebruik van niet-voorgeschreven psychofarmaca lijkt in de afgelopen jaren te zijn toegenomen, waarbij vooral het gebruik van synthetische opioïden, benzodiazepines en andere sedativa zorgwekkend is. Deze middelen worden vaak verkocht in ongeëtiketteerde verpakkingen, wat het risico op misbruik en overdoses vergroot. (2) De groep Chemsex-gebruikers groeit, zowel binnen als buiten de traditionele MSM-community (mannen die seks hebben met mannen). Drugsgebruikpraktijken veranderen, met een toenemend gebruik van middelen zoals 3-MMC, met name onder injecterende Chemsex-gebruikers, wat leidt tot ernstige gezondheidscomplicaties. (3) Veel Oost-Europese migranten en mensen zonder verblijfsstatus gebruiken heroïne, crackcocaïne, alcohol en speed. Zij ervaren aanzienlijke juridische en bureaucratische obstakels bij het verkrijgen van verslavings- en gezondheidszorg. (4) Alleenstaande (voormalig) minderjarige asielzoekers gebruiken in onevenredig hoge mate medicatie zoals Rivotril (een benzodiazepine) en Lyrica (een anti-epileptica en pijnstillend middel). Deze medicijnen worden vaak voorgeschreven zonder voldoende toezicht of begeleiding. (5) Sommige expats maken een snelle overgang van recreatief naar problematisch drugsgebruik, maar hebben moeite om hulp te krijgen vanwege culturele barrières en beperkte toegang tot gezondheidszorg in andere talen dan Nederlands. (6) De online beschikbaarheid van nieuwe psychoactieve stoffen (NPS), zoals 3-MMC en Alpha-PVP/PHP, heeft geleid tot een toename in gebruik, vaak in privéomgevingen. Hierdoor wordt het moeilijk om problematisch gebruik te identificeren en aan te pakken. (7) Jongeren, met name degenen die uit de jeugdzorg komen of dakloos zijn, gebruiken steeds vaker middelen zoals crackcocaïne en 3-MMC. (8) Psychedelica worden steeds vaker gebruikt door mensen met psychische klachten als vorm van zelfmedicatie. (9) Personen die uit detentie komen, krijgen vaak onvoldoende ondersteuning, wat leidt tot een verhoogd risico op overdosering en onderbreking van de behandelingen. Er worden aanbevelingen gedaan voor onderzoeksprioriteiten om deze problemen aan te pakken.

## Discussie en conclusies

Betrouwbare schattingen van populatieomvang en zorgdekking zijn essentieel voor effectieve volksgezondheidsplanning en een effectieve verdeling van middelen. Even belangrijk is de evaluatie van hoe goed bestaande diensten voldoen aan de behoeften van cliënten, aangezien dit invloed heeft op de effectiviteit van de zorg. In Nederland zijn de meeste drugsgerelateerde diensten en beleidsmaatregelen meer dan twee decennia geleden ontwikkeld en niet systematisch geëvalueerd vanuit een cliëntgericht perspectief. De OPAAK-studie vult deze lacune door cruciale inzichten te bieden in de huidige staat van hoog-risico drugsgebruik en relevante diensten in Nederland.

<u>Interpretatie van de populatieschattingen en bredere trends</u>

De bevindingen van deze studie wijzen erop dat de HROU-populatie (opiaatgebruikers) in 2023 iets kleiner lijkt dan in 2012, terwijl de HRCCU-only-populatie (crackgebruikers die geen opiaten gebruiken) groter lijkt dan in 2008. De bevindingen moeten echter voorzichtig worden geïnterpreteerd, aangezien aannames van de Multiplier Method niet volledig werden vervuld. De geschatte populatie omvangen zijn niet betrouwbaar, vooral vanwege de gebrekkige registratie van verslavingszorg in LADIS.

De schattingen van de populatieomvang kunnen beïnvloed zijn door veranderingen in de toegang tot verslavingszorg. Uit het OPAAK-onderzoek blijkt namelijk dat de toegang tot zorg lager lijkt dan tien jaar

geleden. Evenzo meldt de 'Synthetic Opioid Preparedness Scan' van het Trimbos-instituut een groeiend aantal drugsgebruikers die geen gebruik maakt van verslavingszorgdiensten. Dit roept de vraag op of dezelfde populatie minder toegang heeft tot verslavingszorg, of dat andere factoren bijdragen aan deze ogenschijnlijke daling. Een opvallende factor is het groeiende aantal personen dat buiten Nederland is geboren en, volgens onze gegevens, minder in verslavingszorg is dan in Nederland geboren personen. Als specifieke groepen meer obstakels ervaren bij het verkrijgen van zorg, kan dit leiden tot een overschatting van de populatieomvang. Daarnaast hebben experts opgemerkt dat een toenemend aantal patiënten opiaten onderhoudsbehandeling ontvangt via huisartsen. Aangezien niet alle huisartsen aan LADIS rapporteren, kan dit het 'in-LADIS-ratio' verlagen en zo bijdragen aan een overschatting van de HROU-populatie. Verder blijven gespecialiseerde verslavingszorgdiensten voor crackcocaïnegebruikers beperkt, wat het bijzonder lage percentage HRCCU-only-individuen in zorg kan verklaren.

Ondanks deze onzekerheden in de gegevens sluiten de bevindingen aan bij bredere trends. De kleine daling in de HROU-populatie weerspiegelt de langzame daling van HROU-patiënten in het LADIS. Het is belangrijk op te merken dat onderrapportage aan LADIS (zie Hoofdstuk 1) waarschijnlijk de schijnbare daling van HROU-patiënten versterkt, terwijl de verschuiving van OAT-verstrekking naar huisartsen de in-LADIS-ratio kan hebben verlaagd, wat de HROU schatting kunstmatig verhoogt. Rekening houdend met deze factoren ligt de daadwerkelijke daling van de HROU populatie waarschijnlijk ergens tussen de dalende trends die worden aangegeven door de schatting en de verslavingszorggegevens. De toename van de HRCCU-only-populatie komt overeen met de groeiende prevalentie van crackcocaïnegebruik, zoals waargenomen door veldwerkers en gerapporteerd in andere Europese landen. Bovendien rapporteerden vrijwel alle deelnemers van het OPAAK-onderzoek hoog-risicogebruik van crackcocaïne, inclusief bijna 90% van de HROU-individuen. Dit toont aan dat de prevalentie van crackcocaïnegebruik hoog is en dat crackcocaïne in deze populaties momenteel een grotere rol speelt dan opioïden.

<u>Toenemend gebruik van crackcocaïne</u>

Gezien het toenemend crackcocaïnegebruik in Europa lijkt het aannemelijk dat een soortgelijke trend zich ook in Nederland ontwikkelt. Dit roept een belangrijke vraag op: hoe moeten zorgverleners en beleidsmakers reageren op een toename van crackcocaïnegebruik? Het probleem is dat er geen gevestigde farmaceutische behandeling is om verslaving te beteugelen, zoals opiaten onderhoudsbehandeling wordt voorgeschreven aan opioïdengebruikers. Andere landen die te maken hebben met crack-epidemieën, zoals Zwitserland, stellen dat gebruikersruimtes een belangrijk instrument kunnen zijn om een crackepidemie aan te pakken en de schade en overlast te beperken. Zwitserland heeft het gebruikersruimte-model uitgebreid met aanvullende ondersteunende diensten, zoals rustruimtes en hygiënevoorzieningen. In deze studie gebruikten weinig HRCCU-only-individuen gebruikersruimtes en velen gaven aan druggerelateerde attributen te delen, wat de noodzaak onderstreept om het huidige beleid van gebruikersruimtes in Nederland aan te passen om de toegang voor crackcocaïnegebruikers te verbeteren. Ook uit de behoeftenanalyse blijkt dat crackgebruikers behoeften hebben aan meer gespecialiseerde hulpverlening. Rapporten uit andere Europese landen geven aan dat de crackcocaïnescene steeds meer anti-sociaal en gewelddadig wordt. Aangezien regelmatig crackcocaïnegebruik duur is, wenden velen zich tot criminaliteit om hun afhankelijkheid te bekostigen. Hoewel er in Nederland nog geen wijdverbreide meldingen zijn van normoverschrijdend gedrag, is het mogelijk slechts een kwestie van tijd.

<u>Aanbevelingen voor beleid en interventies</u>

Deze studie benadrukt de noodzaak van op maat gemaakte, rechtvaardige, en inclusieve verslavingszorgbeleid en interventies. Er is speciale aandacht nodig om ongelijkheden in verslavingszorg aan te pakken voor de HRCCU-only groep, de vergrijzende HROU populatie, en mensen die niet in Nederland zijn geboren. De hoge, en mogelijk stijgende, prevalentie van crackcocaïnegebruik benadrukt de urgentie van het ontwikkelen van gespecialiseerde behandelings- en harm reduction-diensten voor deze groep. Experts verwachten dat het crackcocaïnegebruik in Europa zal blijven toenemen, wat het belang van voorbereiding ('preparedness') op bijhorende volksgezondheids- en veiligheidsrisico's onderstreept. Gerichte outreach-inspanningen zijn cruciaal om niet-Nederlandse individuen en andere moeilijk bereikbare groepen te verbinden met essentiële diensten, waaronder gebruikersruimtes en HIV/HCV-testen. Daarnaast is een beter begrip van de veranderende behoeften van de vergrijzende populatie van populatie die opioïden gebruikt noodzakelijk om de zorg effectief aan te passen waar nodig. Ten slotte is het verbeteren van de registratie en kwaliteit van verslavingszorggegevens in LADIS van groot belang, aangezien betrouwbare gegevens noodzakelijk zijn voor nauwkeurige inzichten in de verslavingszorg en het vormgeven van evidence-gebaseerd beleid.

## Abbreviations

**3-MMC/ 3-CMC** - 3-Methylmethcathinone/ 3-Chloromethcathinone
**Alpha-PVP/PHP -** α-Pyrrolidinopentiophenone/ α-Pyrrolidinohexanophenone
**AVG** - Algemene verordening gegevensbescherming (General Data Protection Regulation)
**CI** - Confidence Interval
**DCR** - Drug Consumption Room
**DSM** - Diagnostic and Statistical Manual of Mental Disorders
**EMCDDA** - European Monitoring Centre for Drugs and Drug Addiction
**EPD** - Elektronisch patiëntendossier (electronic patient registration system)
**EUDA** - European Union Drugs Agency
**HAT** - Heroin-assisted Treatment
**HCV** - Hepatitis C Virus
**HIV** - Human Immunodeficiency Virus
**HRCCU-only** - High-Risk Crack Cocaine Use without High-Risk Opioid Use
**HRDU** - High-Risk Drug Use
**HROU** - High-Risk Opioid Use
**ICD** - International Classification of Diseases
**IDU** - Injection drug use
**IQR** - Interquartile range
**IT** - Information Technology
**IVZ** - Stichting Informatievoorziening Zorg (Information Provision Care Foundation)
**LADIS** - Landelijk Alcohol en Drugs Informatie Systeem (National Alcohol and Drugs Information System)
**Mainline** - Stichting Mainline
**METC** - Medisch-Ethische Toetsingscommissie (Medical-Ethical Review Committee)
**MM** - Multiplier Method
**NDM** - National Drug Monitor
**NSP** - Needle and Syringe Program
**OAT** - Opioid Agonist Therapy
**OPAAK** - Population size estimate of people with high-risk opioid use and an exploration of people with high-risk use of crack cocaine and other drugs in the Netherlands
**PSE** - Population Size Estimate
**PWID** - People Who Inject Drugs
**ROA** - Routes of Administration
**TDI** - Treatment Demand Indicator
**Ti** - Trimbos-instituut
**UNODC** - United Nations Office on Drugs and Crime
**WHO** - World Health Organization
**Wkkgz** - Wet kwaliteit, klachten en geschillen zorg (Care Sector Quality, Complaints, and Disputes Act)

## General introduction and background

**High-risk drug use (HRDU)**[1] is one of five key epidemiological indicators used by the European Union Drugs Agency (EUDA, formerly EMCDDA) to describe the drug situation in Europe. HRDU is defined as "recurrent drug use that is causing actual harms […] to the person […] or is placing the person at a high […] risk of suffering such harms" (EMCDDA, 2013). A particular focus is on opioid use and injection drug use (EMCDDA, 2022a). Opioid use disorders are responsible for the highest disease burden of all drugs and associated with significant social and economic costs (UNODC, 2017, p.10). Injection drug use increases the risk of infectious disease transmission and other preventable harms.

The last population size estimate (PSE) of **people with high-risk opioid use (HROU)** in the Netherlands was conducted over a decade ago (Cruts et al., 2013). According to that estimate, there were around 14,300 (13,400 – 16,300) people with HROU in the Netherlands in 2012. (It is important to note that this refers to the generally more marginalized populations and not individuals dependent on opioid medication for pain management.) Reliable, up-to-date PSEs are essential for effective public health planning, as they are needed to assess the coverage of care and to determine the appropriate allocation of resources. Coverage of care refers to the extent to which a population in need of a specific health or social service receives those services. However, the most recent data on the coverage of opioid agonist therapy (OAT) and needle and syringe programs (NSP) in the Netherlands is over a decade old and no longer meets the reporting requirements for the EUDA and United Nations Office on Drugs and Crime (UNODC). Updated estimates of the population size and coverage of addiction care in the Netherlands is crucial to ensure that the provision of addiction care services remains adequate. Furthermore, the health and wellbeing of people with HROU have not been systematically evaluated in over a decade. As this population ages, their needs evolve, making it essential to assess whether services still meet their health and social needs.

Another group of interest is **people with high-risk crack cocaine use without high-risk opioid use (HRCCU-only)**. While many individuals with HROU also use crack cocaine, there is a distinct population of people who use crack cocaine with minimal or no opioid use (Cruts & Van Laar, 2010). In the past, there were indications that only a relatively small proportion of people with HRCCU-only accessed addiction care services. A study in the Netherlands found that 41% of people with HRCCU-only used addiction care services compared to 87% of those with HROU (Cruts & Van Laar, 2010). This difference may in part be due to the limited availability of agonist replacement therapy for stimulants in contrast to opioid agonist therapy (Stoops & Rush, 2013). The HRCCU-only population appears relatively large in the Netherlands, with the latest estimate from 2008 indicating approximately 12,000 (10,300 - 15,600) individuals (Cruts & Van Laar, 2010). In 2013 the prevalence of crack dependence was estimated at 0.51% for people aged 15-64 in the three largest Dutch cities (Amsterdam, Rotterdam, The Hague; Pérez et al., 2013). In addition, the EUDA has reported a recent rise in crack cocaine use across Europe (EMCDDA, 2021), with Amsterdam and Antwerp showing the highest levels of crack residues in wastewater analyses among 13 European cities in 2021 (EMCDDA, 2022b). Given these signals from past and present data, it is important to obtain up-to-date information on this population.

Vigilance is also needed regarding **new emerging groups of people with HRDU**. In the Netherlands, several monitors can identify changes in drug use in the general population, such as the General Population Surveys on Health ('Gezondheidsenquête/Leefstijlmonitor') as reported by the National Drug Monitor (NDM), and the Drugs Information and Monitoring System (DIMS). However, these monitors do not effectively capture smaller groups of often marginalized people with HRDU. While the focus often remains on the ageing populations of people with HROU and HRCCU-only, HRDU is a diverse and evolving phenomenon. A recent qualitative investigation by the Harm Reduction Network identified new emerging user groups (e.g., migrants) and drug use patterns (e.g., GHB, pain medication) among clients at different harm reduction facilities in the Netherlands (Van der Gouwe et al., 2022). Additionally, there are signs that chemsex communities represent a big and fast-growing group of people who inject drugs (PWID). It is therefore critical to investigate developments among these emerging HRDU groups to stay up to date with potential new threats to public health.

[1] Formerly referred to as 'problem drug use' (EMCDDA, 2013).

**The National Alcohol and Drugs Information System (LADIS)** is a national registration system for inpatient and outpatient addiction care in the Netherlands. It is the main source of information on treatment demand in addiction care in the Netherlands and the primary data source for calculating PSEs. Data collection for LADIS was suspended between 2015 and 2022 due to issues with the General Data Protection Regulation (AVG) and the need for legal revisions. Since 1 July 2022, data collection has resumed under the amended Care Sector Quality, Complaints, and Disputes Act ('Wet kwaliteit, klachten en geschillen zorg', Wkkgz) (Rijksoverheid, 2024). This enables a PSE of people with HRDU for the first time in years. However, concerns have been raised about the completeness of LADIS data due to registration challenges, which may impact the accuracy of a PSE. Understanding the current completeness of this registration system is therefore essential.

## Aims and goals of this study

The OPAAK study aims to provide updated information on populations of people with high-risk use of opioids and crack cocaine, and to identify new emerging groups of people with HRDU.

The goals of this research are:

1. **HROU PSE and characterization**: To estimate the size of the population of people with HROU and examine their characteristics, including drug use patterns, health, wellbeing, and integration in addiction care services.
2. **HRCCU-only preliminary PSE and characterization**: To evaluate how hard-to-reach the HRCCU-only population is, as part of a pilot study, in order to assess the feasibility of conducting future research on this population. The data collected in the pilot study will be used to generate a preliminary population size estimate of people with HRCCU-only and to assess their drug use patterns, health, wellbeing, and integration in addiction care services.
3. **Needs assessment**: To conduct an assessment of the needs of people with HROU and HRCCU-only.
4. **Emerging groups**: To identify and characterize new emerging groups of people with HRDU that may warrant further research.
5. **Coverages**: To assess the coverage of opioid agonist therapy (OAT), needle and syringe programs (NSP), and the National Alcohol and Drugs Information System (LADIS).

The multifaceted and comprehensive approach of this study addresses both established and emerging aspects of high-risk drug use in the Netherlands. It will thereby generate insights that can be used to improve the provision of addiction care, so that it better meets the needs of (new and changing) high-risk drug users. The findings also aim to inform and support evidence-based public health policies, ensuring resources are allocated effectively to meet the needs of vulnerable populations.

## Study design

### Overall study design

OPAAK is an observational, cross-sectional study utilizing both quantitative and qualitative research methods. The project is organized into three main goals. First, we examined the size and characteristics of the HROU and HRCCU-only populations. The PSE was calculated using the Multiplier Method (for details on the methodology, see the Methods section of Chapter 2). The benchmark was derived from the national registration system for addiction care 'LADIS' for the year 2023, while the multiplier was derived from a fieldwork study performed between July 2023 and July 2024. We aimed to recruit representative samples of people with HROU and HRCCU-only in eight cities with a broad geographical spread across the Netherlands. Data was collected in-person through structured interviews, in which participants completed a questionnaire with field workers. The questionnaire also gathered information about the characteristics, health and wellbeing of these individuals, as well as data for the OAT and NSP coverages. Second, we performed a needs assessment. Data was gathered from non-representative samples of people with HROU and HRCCU-only via focus groups and interviews in different cities in the Netherlands. Third, we aimed to identify emerging trends and groups of people with HRDU. Focus groups were conducted with a range of professionals. All participants provided informed consent.

Participation in the questionnaire was anonymous and data from the focus groups and interviews was pseudonymized.

## Study population

**Target groups**
The overall study population is adults who self-reported HRDU, based on the EUDA definition of HRDU (see below). The study focused on four main target groups:

1. People with high-risk opioid use (HROU), who may also engage in high-risk use of crack cocaine
2. People with high-risk crack cocaine use without high-risk opioid use (HRCCU-only)
3. New emerging groups of people with HRDU
4. People who inject drugs (PWID)

**Case definitions**
**High-risk drug use**[2] is defined as "recurrent drug use that is causing actual harms (negative consequences) to the person (including dependence, but also other health, psychological or social problems) or is placing the person at a high probability/ risk of suffering such harms" (EMCDDA, 2013). This definition is further operationalized by substance.

**High-risk opioid use (HROU)** is defined as: "Use of opioids, including opioid medicines, weekly or more frequently for at least six months of the past 12 months […], not according to medical prescription" or "A medical diagnosis according to current DSM or ICD criteria" (EMCDDA, 2013). This means that patients in OAT and people engaging in the non-prescribed use of any opioids (e.g. heroin, oxycodone, fentanyl) are included in this target group.

**High-risk crack cocaine use (HRCCU)** is defined as "recurrent crack cocaine use" (EMCDDA, 2013). For the purpose of the present study, we apply the definition of high-risk cocaine use to operationalize high-risk crack cocaine use: "Use of [crack] cocaine weekly or more frequently for at least six months of the past 12 months" or "A medical diagnosis according to current DSM or ICD criteria" (EMCDDA, 2013). In the present study, we focus on the group of people with high-risk crack cocaine use without high-risk opioid use (HRCCU-only).

Based on the above definitions, people with high-risk use of *both* opioids and crack cocaine will be categorized as 'HROU'. For example, someone who is in OAT and engages in HRCCU will be categorized in the HROU group, even if they do not use other illicit opioids.

**Injecting drug use** (IDU) is defined as "injecting use of any psychoactive substance(s) not according to medical prescription in the last 12 months" (EMCDDA, 2013). Even if an individual only injected once in the past year they are considered part of the group of people who inject drugs (PWID).

## Ethical approval

The study was granted an exemption from ethics from the Medical-Ethical Review Committee METC NedMec (23-106/DB). In addition, the study went through ethical screening by the Trimbos Ethical Review committee (Trimbos Ethische Toetsing, TET registration number 202309).

## Regulation statement

The study was conducted according to the principles of the Declaration of Helsinki, as revised in 2008. It followed the Dutch code of conduct for scientific integrity ('Nederlandse gedragscode wetenschappelijke integriteit'), with the exception of chapter 5 (pertaining to sanctions and other measures in case of non-compliance), and the Dutch code of conduct for health research of COREON.

[2] In 2012, the EUDA changed the terminology and definition from 'problem drug use' (PDU), which included problematic use of opioids, cocaine and amphetamine, to 'high-risk drug use' (HRDU), which involves substances-specific operationalizations (EMCDDA, 2013).

# Chapter 1. Problems with the registration of addiction care in the Netherlands: An assessment of the coverage of LADIS and implications for the OPAAK study

Analysis of information gathered during the preparatory work for the population size estimates

**Challenges with the registration of addiction care in the Netherlands: An assessment of the coverage of LADIS and implications for the OPAAK study**

# Introduction

Addiction care data provides key information for the development of drug policies and interventions. It offers insight into the scope and nature of patients with problem drug use and it enables estimates on broader populations of people who use drugs. The OPAAK study aims to estimate the size of the population of people with high risk opioid use (HROU)[3]. In order to carry out this study, preparatory work is needed which is based on the national registration of addiction care. During this preparatory work, we encountered numerous issues that hinder the calculation of an accurate population size estimate (PSE). In this report we briefly describe the preparatory work and then outline the problems we identified with the registration of addiction care that are relevant to this study.

## Addiction care in the Netherlands

The National Alcohol and Drug Information System (Het Landelijk Alcohol en Drugs Informatie Systeem, LADIS) is the national registration system of addiction care in the Netherlands. LADIS includes inpatient and outpatient addiction care and is managed by the IVZ Foundation (Stichting Informatievoorziening Zorg, IVZ). While LADIS covers the main institutes for addiction care, it does not contain data from patients with substance use disorders at various other parties, such as some institutes for mental health care, independent psychologists, General Practice Mental Health Workers (POH-GGZ), hospitals, social care, supported living facilities, and judicial institutes (Wisselink, Kuijpers, Kerssies, Van der Slink, 2024).

## Population size estimate

When calculating a PSE, there are two important factors: the benchmark and the multiplier. The benchmark is derived from pre-existing data about an event that is common in the target population, such as drug treatment data. The multiplier is based on the proportion of the target population who experienced this event, for example the proportion who received treatment. To estimate the multiplier, a fieldwork study is needed.

The accuracy of the PSE depends on the accuracy of the benchmark and how representative the field sample is of the population as a whole (UNDCP, 2002; EMCDDA 2004).

## The OPAAK study and context

The aim of OPAAK is to calculate the PSE of people with HROU. For the purpose of this study, the benchmark is derived from the registration system for addiction care, LADIS. The multiplier is based on the proportion of people with HROU in LADIS that is found in the field sample, also referred to as the 'in-LADIS rate'[4].

*The benchmark:* Reporting addiction care data to LADIS is mandatory by law (The Healthcare Quality, Complaints and Disputes Act, Wkkgz) (Wkkgz 2023; Wkkgz Uitvoeringsbesluit 2022). Yet, not all relevant parties do so in practice (IVZ, 2023). It is unclear how incomplete the registration system LADIS is as a result of this underreporting. Moreover, it is unknown to what extent LADIS is missing data due to other factors, such as incomplete reporting of data. Data from LADIS was not available between 2015 and 2022 due to issues with the General Data Protection Regulation. Since 1 July 2022, data collection has restarted and IVZ is working hard to improve the completeness of the data in cooperation with addiction care institutes and relevant parties.

*The in-LADIS rate:* In order to obtain the in-LADIS rate, field study participants are asked where they received help in the past year. As they may not know which organizations a service belongs to, they are asked at which

[3] For the definition of 'high risk opioid use', see: EMCDDA (2013). *PDU (Problem drug use) revision summary.* Luxembourg: Publications office of the European Union.

[4] Note: Not all care providers are registered in LADIS. Therefore we call the multiplier the 'in-LADIS rate' and not the 'in-treatment rate'.

physical locations they received help. **Having a complete and accurate overview of locations that report data to LADIS ('in-LADIS locations') is key for two reasons:**

- Participants are shown a list of in-LADIS locations and are asked if they received care at any of the locations in the past year. The proportion of participants that received help from at least one location makes up the in-LADIS rate. If the overview is incomplete, it yields an inaccurate in-LADIS rate.
- The overview of in-LADIS locations is also critical for recruitment. Participants can only be recruited at locations that do not report data to LADIS. If participants were to be recruited at in-LADIS locations, there would be a 100% chance of them being in LADIS, which would generate a faulty PSE.

In this report we describe the problems we encountered while creating this overview of in-LADIS locations.

## Aim

**The aim of this report** is to highlight problems with the registration of addiction care. The report is not a comprehensive evaluation of LADIS, but rather it highlights issues that we identified within the framework of the OPAAK study. The information in this report helps interpret the accuracy of the PSE, including how complete the benchmark (LADIS) is and how reliable the multiplier is (based on the in-LADIS rate).

## Methods

In this section we describe the preparatory work for the PSE, during which we encountered problems with the registration of addiction care. **The goal of this preparatory work** was to create an overview of locations and services for people with HROU in 2023 that report data to LADIS. As described above, this is key for the recruitment of participants and for the collection of data for the PSE. An overview was made for each of the eight cities of recruitment: Amsterdam, Rotterdam, The Hague, Utrecht, Eindhoven, Haarlem, Groningen, Heerlen.

### Terminology

Addiction care in the Netherlands is structured as follows:

- An addiction care institute ('instelling voor verslavingszorg') can operate in one or multiple cities or provinces, and it can operate at one or multiple locations ('locaties').
- A location is defined as a physical location with a unique postal address. Each location can provide multiple services ('hulpaanbod') including treatment and other care and support services.
- One location can provide multiple services. Not all services at a location are necessarily reported to LADIS; some services may be reported while others may not be reported.
- Some addiction care institutes operate independently, while others belong to an overarching group (e.g. *Brijder, Triora, Reakt, Youz,* and *Antes* all belong to *Parnassia Group*).

### Procedure

Steps to generate the overview of in-LADIS locations and services:

1. Obtain a list of all **addiction care institutes** that reported data to LADIS.[5]
2. Identify which addiction care institutes operate in each of the **8 cities** of recruitment.
3. Contact the institutes for a list of their **locations** that serve people with HROU in each of the 8 cities.
4. Obtain a list of all **services** offered at each location and specify which ones are reported to LADIS.[6]
5. **Triangulate** the information with data from previous studies and additional Internet searches.
6. Discuss any **inconsistencies** with the institutes and locations.
7. Finalize the list of in-LADIS locations and services.

[5] The most recent list of addiction care institutes available at the start of this research was from 2021.

[6] Adaptation: Employees at institutes who we spoke to did not know what data is reported to LADIS. So instead we asked if clients needed to be registered in the electronic patient registration system ('elektronisch patiëntendossier', EPD) to make use of a service. We did this based on the assumption of IVZ that all locations of an institute should use the same EPD, and that all data in an EPD should be sent to LADIS. We were unable to verify this assumption.

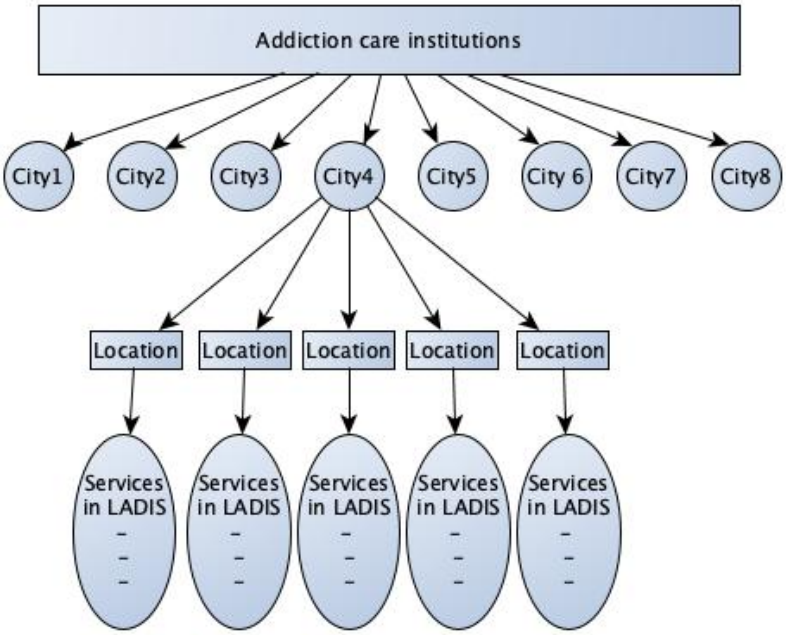



Figure 1. Structure of information that was sought during data collection.

## Findings

We present the main problems with the registration of addiction care that we identified during our work and which are relevant to the PSE in the OPAAK study. The challenges pertain to the broader registration system (macro level), the addiction care institutes (meso level), and the locations at which addiction care services are provided (micro level). Additional non-registration related issues are also discussed.

### Macro-level: Registration system

#### 1. Data in LADIS is linked to addiction care institutes but not to the specific locations.

The main problem that we encountered in our investigation is that a complete and up-to-date overview of in-LADIS locations is not readily available. It is only possible to see which addiction care institutes but not which specific locations provide data to LADIS. This means that the overview of in-LADIS locations for a PSE must be generated from scratch. Generating the overview of in-LADIS locations took place over the course of 11 months (January – November 2023). We originally planned 10 days for this task, based on the assumption that such overviews should be readily available. In the last PSE study ten years ago (Cruts et al., 2013), system administrators at addiction care institutes had access to these overviews. IVZ was in direct communication with these professionals. However, in 2023, the task of the system administrators has typically been delegated to external IT companies. We were unable to reach the responsible parties. The current situation therefore makes it near impossible for PSE studies to be carried out on a regular basis.

This lack of transparency also hampers IVZ from being able to accurately check if an institute reported data from all its locations or how complete the data is. Similarly to us, IVZ is unable to see which locations of addiction care institutes send data, and it is unable to check what data is *not* sent to LADIS (J. Wisselink, personal communication, April 2024). To overcome this, IVZ conducts quality controls in close communication with addiction care institutes. Institutes are asked if they recognize themselves in the data that they provided and to identify gaps in the data. However, this feedback is based on the goodwill of institutes rather than full transparency at the data registration level.

### 2. The definition of 'addiction care' is vague and not implemented well.

The treatment demand indicator (TDI) provides a structure for reporting drug treatment data to the European Union Drugs Agency (EUDA; previously EMCDDA). The Healthcare Quality, Complaints and Disputes Act (Wkkgz) in the Netherlands is in line with the TDI. The Wkkgz defines 'addiction care' as a specialized form of care for people who have problems with, or have become addicted to, the use of psychoactive substances[7]. Addiction care includes treatment ('verslavingszorg') and other care for people with substance use disorders ('zorg voor verslaafden') such as harm reduction services. In other words, 'addiction care' is considered care that takes place for problems with substance use, but not care where patients (also) have a problem with substance use.

In practice this definition is not clear and addiction care institutes struggle with it. Various stakeholders that we spoke to indicated that some institutes, which deliver specialized addiction care (and *should* report to LADIS), do not consider themselves to fall under that category and therefore do not deliver data to LADIS. As a result, LADIS does not provide a complete overview of addiction care in the Netherlands.

Moreover, various services – such as drug consumption rooms (DCR's), protected living facilities and night shelters – are not consistently reported to LADIS. These services can be found in both in-LADIS and non-LADIS institutes. However, according to the broad definition of the TDI and the Wkkgz, DCR's and protected living facilities fall under the umbrella of 'addiction care' and should be delivered to LADIS. The fact that one type of service is not consistently included in LADIS therefore complicates the picture even further. For example, it would be useful to have a complete and up-to-date list of DCR's, as this is often requested and needed by (international) stakeholders, such as the EUDA, Harm Reduction Network, researchers and policy advisors.

### 3. The registration of clients in LADIS and the registration of OAT patients are both incomplete.

The accuracy of a PSE can be enhanced by using a registration system that is complete and/or by using multiple registration systems. However, LADIS is incomplete and it is the *only* relevant registration system that can be used in the present PSE. The registration of OAT clients is incomplete, as not all addiction care institutes provide data. Moreover, an increasing number of patients have been receiving their OAT from GPs, particularly since the covid pandemic, and these are not always reported to LADIS either. The number of OAT patients in LADIS is therefore incomplete. The Netherlands once had a mandatory OAT registration system but it was discontinued in 2012. If there were a complete registration of OAT patients, then this sample could be used to greatly enhance the accuracy of the PSE.

An example of good addiction care registration is Germany:

- They have a mandatory (complete) registration system of patients in OAT: the Substitution Register at the Federal Institute for Drugs and Medical Devices (*Substitutionsregister am Bundesinstitut für Arzneimittel und Medizinprodukte, BfArM).*
- Germany also has the Facility Register of the German Monitoring Centre for Drugs and Drug Addiction (*Einrichtungsregisters der Deutschen Beobachtungsstelle für Drogen und Drogensucht, DBDD*), which is a central registry to determine the total number of specialized addiction care facilities in Germany.
- In addition to that, there are two (incomplete) registration systems: the German Addiction Care Statistics (*Deutschen Suchthilfestatistik, DSHS)* and the Berlin Addiction Support Statistics (*Berliner Suchthilfestatistik)*. By using these in combination with the register of facilities and the register of OAT, it significantly enhances the accuracy of a PSE and provides an up-to-date overview of the provision of addiction care in Germany (Kraus et al., 2019).

## Meso-level: Addiction care institutes

### 4. Institutes do not have readily-available information about their locations.

Employees of addiction care institutes often referred us to outdated online sources about the institute's locations or sent overviews that contained incomplete or outdated information. We noticed this through triangulation with other data sources and additional Internet searches. For example, institutes did not always include locations for heroin-assisted treatment (HAT), DCR's, and other services in their overview. Lists of

[7] Source: https://wetten.overheid.nl/BWBR0037173/2023-10-05#Hoofdstuk1

locations were more often incomplete for large institutes, especially if they belonged to an overarching group (e.g. Parnassia Group). When we discussed these issues with the employees, they were sometimes unaware of the existence of locations identified by us, despite us having verified that they are operating. Thus, it is possible that we missed further locations as a result of this and that our locations-overview is incomplete.

### 5. Information about which services are reported to LADIS is not easily accessible.

To complete our overview of in-LADIS locations, we also needed to know which specific services are reported to LADIS and which are not. That is because one location can include services that are reported and services that are not reported to LADIS. Addiction care institutes use a LADIS-export button to send their data to LADIS. However, employees at institutes that we spoke to did not know what data is sent to LADIS, or who would have this type of information. In fact, most employees that we spoke to were even unaware of the existence of LADIS. Therefore, we were unable to identify for any institute which services are reported to LADIS. For the OPAAK study, we tried to circumvent this problem by asking which services require clients to be registered in the EPD (see methodology adapted step 4). However, we cannot be certain of the accuracy of our overview of in-LADIS locations and services because of this.

## Micro-level: Locations providing addiction care services

### 6. Registration burden and lack of user-friendly IT systems.

The addiction care sector faces a significant registration burden, with staff under increasing pressure to input extensive patient data. Various stakeholders highlighted this issue, describing data entry as cumbersome and inefficient. Additionally, several addiction care institutes appear reluctant to engage in constructive collaboration to address these challenges. A recent evaluation from another study supports these findings, identifying registration processes as time-consuming due to the high volume of data and the absence of user-friendly IT systems (Plomp & Legemaate, 2024, p. 285).

### 7. Incomplete and inconsistent reporting of data.

Experts claim that patient registration forms are often not being completed well by staff at addiction care locations. This is in part due to the registration pressure and inconvenient registration systems mentioned above. Some experts claim that this is only relevant for a small number of patients. Others claim that gaps in the data happen frequently. It is not clear how institutes deal with incomplete patient data. If data does not meet certain requirements – for example, because there are too few data points – then data may not be reported to LADIS. We also found that some stakeholders are more willing to deliver data than others and this leads to inconsistent reporting of services to LADIS. For example, according to our findings, not all in-LADIS institutes report their assisted living facilities to LADIS. Moreover, we found that not all institutes seem to use the electronic patient registration system (EPD) consistently.

### 8. Underreporting of data

There also appears to be substantial underreporting. When a patient receives care for problems with their substance use disorder, an addiction record must be created for the data to be sent to LADIS. However, in practice, this does not always happen at numerous institutes (J. Wisselink, personal communication, April 2024). Moreover, there are ongoing discussions about whether dual-diagnosis clients should be included in LADIS, even if they primarily receive care at mental health institutes. Taken together, these issues with incomplete or inconsistent reporting of data compromises the accuracy of LADIS.

### 9. Limited distinction between drug categories

Another important observation is the limited distinction between certain drugs in the registration system. For example, the system offers the category ‘cocaine’, followed by a question on how it is used (smoked or snorted), rather than simply providing the categories ‘cocaine’ and ‘crack cocaine’. Staff at addiction care institutes do not always complete the question on how the drug is used, leading to an incomplete understanding of what percentage of the ‘cocaine’ group is actually crack cocaine users (J. Wisselink, personal communication, April 2024). Not having an accurate differentiation of subgroups hinders our understanding of what subgroups enter addiction care and prevents the accurate estimation of population sizes.

## Non-registration related issues

### 10. Locations of addiction care services change frequently.

Many locations of addiction care services closed and reopened at different addresses or merged with different institutes over the past decade. We observed this when triangulating our data with data from previous studies, including overviews of OAT, HAT, and DCR locations that were generated by the Harm Reduction Network in 2021. Just two years later approximately half of the locations no longer existed, had moved to a new address, or fell under a different care provider. Moreover, many new (smaller) institutes have emerged. Thus, the addiction care landscape is fragmented. Continuity of care needs to be better secured.

### 11. High-threshold admission criteria for services reported to LADIS.

Some addiction care institutes that report data to LADIS have high-threshold admission criteria for clients. This may consequently exclude certain vulnerable populations from life-saving services. For example, some in-LADIS institutes required clients to be abstinent and older than age 35. Moreover, DCRs from in-LADIS institutes appear to be limited to their clients who are *already* in treatment. However, DCR's are generally intended to be low-threshold services, open to anyone, to be able to reach even the most vulnerable populations and provide a pathway into care. Such low-threshold DCRs are rarely offered by addiction care institutes and instead provided by other parties such as the Salvation Army ('Leger des Heils').

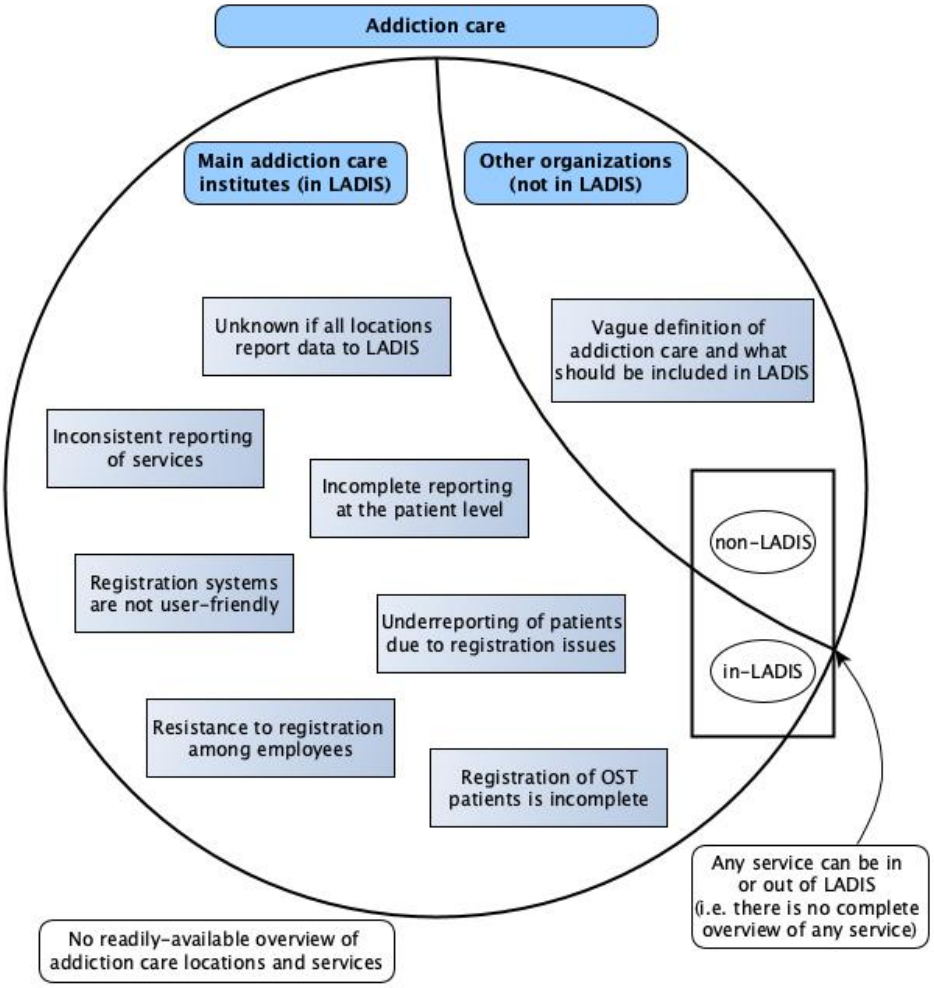



Figure 2. Overview of key issues with the registration of addiction care in the Netherlands.

## Conclusions

Various issues with the registration of addiction care in the Netherlands hamper an accurate overview of the number of patients with substance use disorders. Challenges exist at different levels, from a vague definition of addiction care to inconsistent reporting of certain services to incomplete registration of patients. Information about addiction care is fragmented and the quality of data is not guaranteed. Gaps exist at every level of the addiction care registration, which makes it difficult to understand how complete or reliable the data in LADIS is. A recent evaluation mirrors our findings:

> "*There are doubts about the completeness, reliability and clarity of the data supplied. […] There are differences in interpretation, problems surrounding the EPD systems, and not all health care providers register patient data in a timely and accurate manner*" (Plomp & Legemaate, 2024, p.285).

It should be noted that our report is not a complete investigation of registration issues; it merely describes issues that we encountered during our work. Overall, our findings highlight the need for a central registration of addiction care, including locations and services, that is complete, accessible, transparent, user-friendly, and up-to-date.

With regard to the OPAAK-study, the above mentioned issues hamper a reliable PSE. It is difficult to say how complete the benchmark is or how reliable the estimated in-LADIS rate is. We continuously encountered new information about in-LADIS locations that was not provided to us in the first round of investigation. We hope that through triangulation and further investigation we generated a fairly accurate overview, but we cannot be certain of this.

# Chapter 2. Population size estimates and characteristics of people with high-risk opioid use (HROU) and people with high-risk crack cocaine use without high-risk opioid use (HRCCU-only)

Analysis of data from the questionnaire and from LADIS

**Population size estimates and characteristics of people with high-risk opioid use (HROU) and people with high-risk crack cocaine use without high-risk opioid use (HRCCU-only)**

# Rationale and Aims

Reliable and up-to-date data on populations with high-risk drug use are essential for effective public health planning and resource allocation. However, the most recent population size estimates (PSE) for people with high-risk opioid use (HROU) and people with high-risk crack cocaine use without high-risk opioid use (HRCCU-only) in the Netherlands date back to 2012 and 2008, respectively (Cruts et al., 2013; Cruts & Van Laar, 2010) (see 'General introduction' for details). This highlights an urgent need for updated estimates. Various indirect methods can be used to estimate the prevalence of hidden populations (EUDA Data, 2024). Given the limited availability of required data in the Netherlands and the need for comparability with previous estimates, we chose to employ the Multiplier Method. This approach estimates population size based on the proportion of high-risk drug users who accessed a treatment service in a given period. This proportion is typically derived from a field study involving a representative sample of the target population.

National experts were consulted to determine how to investigate the HRCCU-only population (i.e., people who use crack cocaine but not opioids). Based on the latest available LADIS data at the time, and prior research findings indicating that HRCCU-only individuals have less contact with addiction care services (Cruts & Van Laar, 2010), experts expected this group to (still) be of substantial size. Additionally, the European Union Drugs Agency had reported rising crack cocaine use in several European countries. However, challenges in identifying HRCCU-only individuals were evident in a 2008 study (Cruts & Van Laar, 2010), where only about 100 of the targeted 400 participants were successfully recruited. Moreover, experts had not observed clear indications of growth in this population. Anticipating similar difficulties in recruiting HRCCU-only participants, we opted to conduct a pilot study with a smaller sample size to gather preliminary insights into this population.

The aims of this work package were:

1. *HROU population estimation*: To provide a PSE for people with HROU and examine their characteristics, including drug use patterns, health, wellbeing, and integration in addiction care services.
2. *Exploration of HRCCU-only population:* To evaluate how hard-to-reach the HRCCU-only population is to determine the feasibility of conducting future research on this group. Additionally, the study seeks to provide a preliminary PSE of people with HRCCU-only and analyse drug use patterns, health, wellbeing, and integration in addiction care services.
3. *Comparative analysis:* To identify potential differences between the two target groups by comparing their characteristics.

# Methods

## Population Size Estimate method: Multiplier Method

The European Union Drugs Agency (EUDA) gathers data on high-risk drug use (HRDU) as one of five key epidemiological indicators for monitoring the drug situation in Europe. Reitox Focal Points, such as the Trimbos Institute, are required to regularly provide updated estimates of population sizes and service coverages to the EUDA. As noted earlier, we chose to estimate population sizes using the Multiplier Method to be able to compare PSEs with previous estimates and because only limited data is available for PSEs in the Netherlands.

**Multiplier Method**

The Multiplier Method (MM) is an indirect method for calculating a population size estimate (PSE) that is particularly useful for populations that are hard-to-reach. It relies on a *benchmark*, which is derived from pre-existing data about an event that is common in the target population, and a *multiplier*, which is based on the estimated proportion of the target population who experienced this event (UNDCP, 2002). To align the

multiplier with the benchmark, both data sets use the same one-year time frame. Key assumptions of the MM are that the benchmark data is accurate, the population is relatively stable, and the study sample is sufficiently representative of the population as a whole (Hickman & Taylor, 2005). The formula used is:

> Benchmark x multiplier = Total population estimate
> (Where the multiplier is based on the estimated proportion.)

**Benchmark and multiplier in OPAAK**
In OPAAK, the *benchmark* was derived from the National Alcohol and Drug Information System (Het Landelijk Alcohol en Drugs Informatie Systeem, LADIS). LADIS is the national registration system of addiction care in the Netherlands, which includes inpatient and outpatient care. Specifically, the benchmark represented the number of people with HROU registered in LADIS in 2023.

The *multiplier*, referred to as the 'in-LADIS rate', was derived from a fieldwork study conducted between July 2023 and July 2024. The in-LADIS rate is the inverse of the proportion of people with HROU who received care in the past twelve months at a service that reported data to LADIS. In order to obtain the in-LADIS rate, two steps were needed (see Chapter 1 for details):

1. For each recruitment city, we created a list of service providers, including their locations (addresses) and the specific services they reported to LADIS in 2023. Recruitment was restricted to locations that did *not* report to LADIS to prevent inflating the in-LADIS rate to 100%.
2. Participants in the fieldwork study were shown the list of in-LADIS locations and asked if they had received care from any of the listed service providers in the past year. Those who confirmed receiving care at one of these locations were categorized as "in-LADIS".

## Data collection and sampling method

**Data collection**
Data for the PSEs was collected through structured interviews, in which participants completed a questionnaire together with a trained field worker. This approach was chosen because it enhances data quality and completeness while minimizing participant burden. To prevent duplicate participation, a fixed team of field workers operated in one city at a time. The questionnaire, available in both Dutch and English, was programmed using Jambo Software (version 3.2) and administered on iPads. All data was stored securely at the Trimbos Institute in full compliance with data protection security regulations. Participants received 10 Euro cash as compensation for completing the interview.

Fieldwork was conducted by Mainline, a foundation committed to improving the health and quality of life of people who use drugs through information provision, referral, and advocacy. Mainline's strong reputation among marginalized drug-using populations fostered trust and enhanced willingness to participate in research. Through their daily work at Mainline, field workers were skilled in communication and engagement techniques to effectively interact with vulnerable populations. Mainline's expertise and familiarity with the target populations and key recruitment locations made them particularly well-suited for conducting recruitment and data collection in this study.

**Sampling method and recruitment strategy**
Samples of people with HROU and HRCCU-only were recruited from eight cities in the Netherlands. A random sampling method was employed, complemented by snowball sampling, where participants referred others to the study. Although respondent-driven sampling is often considered best-practice, it is resource-intensive and presents its own challenges in hard-to-reach populations (Bryant, 2014). Therefore, a comprehensive recruitment strategy was developed to ensure a robust and representative sample without relying on seeds:

- *Geographic coverage:* Recruitment took place in eight geographically diverse cities: Amsterdam, Rotterdam, Utrecht, Eindhoven, Haarlem, Den Haag, Groningen, Heerlen. The first five cities were selected because they had been included in a previous PSE study (Cruts et al., 2013), Den Haag was added as one of the four biggest cities in the Netherlands, while Groningen and Heerlen were included to enhance regional representation.
- *Proportionate sampling:* Recruitment targets reflected the population's gender distribution and each city's population size (see 'Proportionate sampling' below).

- *Inclusivity:* To accommodate participants from diverse backgrounds, the questionnaire was available in both Dutch and English.
- *Recruitment locations:* Participants were approached in various locations, including public spaces and service sites for people who use drugs (e.g. social shelters, residential facilities). Field workers sometimes collaborated with stakeholders like street doctors and police to identify suitable recruitment sites. They even recruited at night to increase the likelihood of identifying the target groups at certain locations.

*Proportionate sampling*
Sampling goals were based on the relative number of people with HROU in each city (using the latest reliable LADIS-data from 2015) and each city's general population data (also using 2015 data for consistency). Recruitment targets were as follows: Amsterdam 24%, Rotterdam 24%, Den Haag 12%, Utrecht 9%, Eindhoven 7%, Haarlem 7%, Groningen 12%, Heerlen 5%. In addition, recruitment aimed to reflect the gender breakdown of the HROU population, which is approximately 82% men in the European Union (EUDA, 2024) and 86% men in the Netherlands (Cruts et al., 2013). Thus, the recruitment target was set between 82% and 86% men. These sampling goals applied to both the HROU and the HRCCU-only groups. If recruitment challenges arose in one city, numbers could be balanced by increasing recruitment efforts in another.

*Anticipated recruitment challenges*
Several recruitment challenges were anticipated. First, a 2008 study encountered difficulties in recruiting sufficient HRCCU-only participants (Cruts & Van Laar, 2010), suggesting that this group may be particularly small or hidden. Second, the relatively low prevalence of injection drug use in the Netherlands means that recruiting people who inject drugs (PWID) might be challenging. (A sufficient number of PWID is needed for the needle syringe coverage calculation in Chapter 3) Finally, the number of patients in opioid agonist therapy (OAT) in the Netherlands appears to have declined over the past decade (Informatie Voorziening Zorg, 2023), indicating a potentially smaller and hard-to-reach HROU population. Although it is unclear whether this reflects a true reduction or merely incomplete registration of addiction care (see Chapter 1).

## Eligibility criteria and target groups

Participants were eligible for inclusion if they were aged 18 or older, had resided in the Netherlands for at least three months, and met the EUDA definition for HROU and/or HRCCU. HROU was defined as use of non-prescribed opioids at least once a week for at least six of the past twelve months and/or being currently in OAT. HRCCU was defined as use of crack cocaine at least once a week for at least six of the past twelve months (see 'Case definitions' in 'Study Design').
The present study focused on two mutually exclusive target groups:

- People with high-risk opioid use (HROU), who may or may not engage in high-risk use of crack cocaine, and
- People with high-risk crack cocaine use without high-risk opioid use (HRCCU-only).

For a visualization of these target groups and their relation to each other, see Figure 2 in 'Part 2: 3.2 Sample composition'.

## Sample size calculation

An adequate sample size is required for a reliable PSE estimate (Kadam & Bhalerao, 2010). Based on the 2012 estimate of 14,300 people with HROU in the Netherlands (Cruts et al., 2013), we calculated a required sample size of 374 participants, using a 5% common margin of error and a 95% confidence level. To account for potential drop-outs and incomplete responses, 10% was added, setting the target sample size at 411 participants. For the HRCCU-only group, the recruitment target was set at 100 participants due to the exploratory nature of this study. It is important to note that a reliable PSE requires around 400 participants, so the PSE for HRCCU-only is only preliminary and should be interpreted with caution.

## Questionnaire

The questionnaire was adapted from the survey used in a 2012 PSE study in the Netherlands (Cruts et al. 2013). Drafts were developed in an iterative process with national experts, including scientific researchers from various organizations and senior staff and field workers from Mainline. Where possible, validated tools, or items from validated tools, were incorporated. The questionnaire was piloted with three individuals who use drugs, yielding positive feedback on its comprehensibility, acceptability, relevance, and feasibility. Adjustments were made based on their input. The final questionnaire covered a range of topics, including service use, substance use patterns, injection drug use and risk behaviour, physical and mental health, overdoses, treatment experiences, quality of life, recovery, and social integration and discrimination. The full questionnaire is available in Appendix A. The average completion time was 15-20 minutes.

**Tools used**

*Opiate Treatment Index - Health Symptoms Scale (OTI-HSS)*

The OTI-HSS (Darke et al., 1991) is a self-report measure to assess the physical health of people who use opioids. It includes a checklist of fifty symptoms related to health concerns in this population. For this study, nine symptoms most relevant to the target population were selected in consultation with multiple researchers. These included shortness of breath/difficulty breathing; persistent cough; chest pains; heart flutters/racing; abscesses/infections from injecting; intestinal problems/ diarrhoea/ constipation; trouble sleeping; teeth problems; and forgetting things. Participants indicated which symptoms they currently experienced and could list additional symptoms in an open-response field.

*Patient Health Questionnaire-2 (PHQ-2)* and *Generalized Anxiety Disorder 2-item (GAD-2)*

The PHQ-2 (Kroenke et al., 2003) and the GAD-2 (Kroenke et al., 2007) are brief validated screening tools for depressive disorder and generalized anxiety disorder, respectively. Each consists of two items. The PHQ-2 includes 'Little interest or pleasure in doing things' and 'Feeling down, depressed, or hopeless', while the GAD-2 includes 'Feeling nervous, anxious or on edge' and 'Not being able to stop or control worrying'. Participants rated how often they experienced each symptom in the past 2 weeks using a 4-point Likert scale (0=not at all, 1=several days; 2=more than half the days, 3=almost every day). Total scores range from 0 to 6, with a score of 3 or higher indicating a positive screen for depression or generalized anxiety. A positive screen suggests that further evaluation is needed to determine if the individual meets the diagnostic criteria for depressive or generalized anxiety disorder. Both tools have a high sensitivity and specificity for these conditions (e.g., Sapra, Bhandari, Sharma, Chanpura, & Lopp, 2020; Löwe, Kroenke, & Gräfe, 2005).

*7-item Manchester Short Assessment of quality of life (MANSA-7)*

The MANSA-7 is a shortened version of the MANSA (Priebe et al., 1999), designed to assess quality of life. It evaluates satisfaction with life as a whole as well as six specific life domains: living situation, physical health, mental health, social relationships, daily activities and financial situation. To facilitate answering these questions in an interview setting, the original 7-point Likert-scale was adapted to a 10 point scale (1=very bad, 10=very good). Scores are totalled and then divided by the number of questions, with higher scores indicating better quality of life. Since the MANSA-7 is not validated, normative scores are not available.

*INSPIRE-O*

The INSPIRE-O (Moeller et al., 2023) is a 5-item validated measure of recovery. Participants rate their agreement with five statements, including 'I feel supported by other people', 'I have hopes and dreams for the future', 'I feel good about myself', 'I do things that are important to me', and 'I feel in control of my life'. To facilitate answering these questions in an interview setting, the original 5-point Likert-scale was adjusted to a 10 point scale (1=very bad, 10=very good). For scoring, responses were recalibrated to the original scale, then totalled and multiplied by 5, resulting in a final score ranging from 0 (low recovery support) to 100 (high recovery support).

## Statistical analyses

Data was analysed using descriptive statistics in R software (version 4.4.1). Missing data was not imputed and analyses were performed on available cases for each variable. Consequently, the sample size varied across items due to missing values as well as routing logic in the questionnaire. Most items used predefined response categories unless noted otherwise.

# Results

# Part 1. Recruitment: observations and issues

This section outlines various challenges that field workers encountered during recruitment. These observations are relevant for interpretating the PSE, as they influence how representative the study sample is of the overall population. A less representative sample can lead to a less accurate PSE, potentially skewing the results and limiting their generalizability. Participants were recruited in a wide range of locations, including service facilities for people who use drugs (e.g., social shelters, residential facilities, drop-in/walk-in centres), as well as public spaces (e.g., on the streets, in parks, in forests).

## 1.1 Issues encountered during recruitment

During recruitment, several challenges and insights emerged, particularly regarding interactions with institutions, accessibility of the target group, and operational bottlenecks.

Access to Residential Facilities
To reach respondents, Mainline field workers often relied on access to social care institutions. While Mainline is well-known in drug-related services such as consumption rooms, drop-in centres, and methadone programs, many of these are managed by addiction care institutions that report data to LADIS. Consequently, these locations were excluded from recruitment, necessitating greater reliance on social shelters and residential facilities. However, Mainline is less well-known at these locations. Additionally, terms like "interviews" or "research" sometimes led institutions to deny access or refer to their communication departments. Convincing residential institutions of the study's value was occasionally difficult, requiring extensive communication. Despite these efforts, some institutions refused access without explanation. In cities where these institutions managed a large part of the housing services, this had a major impact on access to the target group.

Access Issues After Approval
Even after gaining permission to access facilities, problems frequently arose. On multiple occasions, facilities denied entry on the scheduled day due to miscommunication or incidents (e.g., emergencies or deaths) that restricted access from external visitors.

Identifying Respondents
Identifying whether the target groups were present within facilities often proved challenging. When field workers called the services, they specified that they were looking for people who use opioids or crack cocaine. However, staff frequently lacked detailed knowledge about which substances residents used, or even a clear understanding of what the substances are. This often led to confusion about who qualified as an opioid user or which substances were classified as opioids. Consequently, it was common for residents or clients to be using substances other than opioids or crack cocaine, resulting in the target groups not being present at the identified locations.

Recruitment Ratio: Opioid and Crack-Cocaine Users
The study aimed to recruit four times as many opioid users (with or without crack cocaine use) as crack-only users (without opioid use). However, fieldwork revealed that the actual ratio in many locations was closer to 50/50, with crack-only users sometimes being easier to locate than opioid users. This ratio appeared to be similar across different types of locations, including both service facilities and public places.

Preventing Duplicate Participation
To prevent that respondents participated multiple times, Mainline used a consistent team of field workers in each city and aimed to complete recruitment quickly. Despite these efforts, duplicates might have occurred, particularly in Rotterdam, where recruitment had to be spread over a longer period of time, making it more difficult to recognize respondents.

Impact of Repression and Distrust

Recruitment was more difficult in cities like Rotterdam and Eindhoven that seem to have a more repressive approach to homeless people and people who use drugs, as reported in the media. In these cities, Mainline encountered more mistrust from the institutions, which complicated the recruitment process. Potential respondents also appeared more wary compared to other cities.

Target Group Accessibility
Although gaining access to institutions sometimes proved complicated due to bureaucracy and unfamiliarity with Mainline and Trimbos, the target group itself was generally easily approachable. Once field workers had gained access to a service or when they spoke to people on the street, they generally received positive responses. The 10 Euro incentive was appreciated but not the primary motivator for participation. Many respondents were familiar with Mainline and enjoyed participating in the research, often sending thank-you notes afterwards.

## 1.2 Observations in each city

Recruitment experiences varied across the eight cities, with some posing more challenges than others:

*Amsterdam:* Recruitment was most successful in Amsterdam due to Mainline's strong local presence and established relationships with users and institutions. The target group was easily encountered in public spaces and 'on the streets'. Nevertheless, it became difficult towards the end of recruitment to reach the target sample size of people who use opioids.

*Rotterdam:* Recruitment was considerably more difficult in Rotterdam than other cities. Key locations that Mainline is familiar with were excluded because they were 'in-LADIS'. Another institution with a lot of residential facilities denied access. At other locations, the staff was often unfamiliar with Mainline, which made gaining access difficult. Moreover, many visits to residential areas and public spaces, which are known as 'nuisance locations', were not fruitful, because the target group was not present at the time. Recruitment during the winter further complicated efforts, as not many individuals were found 'on the streets'.

*Den Haag:* Also in Den Haag, a number of larger locations were 'in-LADIS'. Bureaucracy at housing institutions slowed down the process (e.g., due to referrals to head offices and communication departments), slowing down access. Eventually, alternative contacts facilitated access.

*Groningen:* Recruitment was smooth due to a well-frequented location where various organizations were located which are not 'in-LADIS'. Field workers also came here regularly as part of their day-to-day work for Mainline. This made it easier to identify and approach the target group.

*Utrecht:* In Utrecht, recruitment went smoothly, mainly because it took place in the summer, when target group members were present in public spaces. Access to a number of residential locations also went smoothly due to Mainline having good contacts here.

*Eindhoven:* Eindhoven posed the most challenges, such that we were only able to achieve half the target sample size. Many recruitment locations were 'in LADIS', which limited access. A few key social care institution refused to cooperate, despite multiple attempts from both Trimbos and Mainline to talk to the locations and even management. This ultimately affected our ability to obtain the intended sample size. At other organizations, miscommunication led to rejections on the day of the visit on several occasions. Finally, the time of year added to the challenge, given that fewer people are on the streets in autumn and winter. It is worth noting that already in the last research from 10 years ago (Cruts et al., 2013), field workers encountered significantly more challenges in Eindhoven than other cities. A field worker who collected data at the time recalled that the organizations were not cooperative, the target groups were chaotic, little care was available, and the care *that* people received was below standard (JP. Kools, personal communication, October 2024).

*Haarlem:* No major issues arose in Haarlem. Good local contacts and cooperative institutions enabled effective recruitment.

*Heerlen:* Supportive and cooperative residential institutions ensured swift and successful recruitment.

## 1.3 Conclusions

Overall, recruitment challenges were encountered in most cities, except Amsterdam, Utrecht, and Haarlem. The most challenging city was Eindhoven, where only half the target sample size could be reached. Recruitment success was influenced by several factors:

- *Institutional cooperation:* Many addiction care locations were registered in LADIS, which is a positive indicator of the coverage of LADIS. However, this made participant recruitment more challenging. In cities with few 'non-LADIS' facilities, the lack of cooperation from these facilities significantly hampered recruitment efforts, which made it difficult to reach sample size targets.
- *Dynamic target groups:* People who use drugs are dynamic and move around, meaning they cannot reliably be found at certain locations. This issue was heightened during the present recruitment period as police and law enforcement continuously sent drug-using individuals away from locations, as reported in the media. This further complicated access to the target groups and may have limited the representativeness of the sample. It also underscores that recruitment just provides a snapshot of a population at any given moment, and that sample representativeness is not guaranteed.
- *Seasonal timing:* Recruitment was easier in spring and summer than in autumn and winter.
- *Repressive drug policies:* Field workers noted that individuals were less inclined to talk about drugs or participate in this research in cities with more repressive drug policies.

It is difficult to estimate to what extent these recruitment challenges impacted the representativeness of the sample. Findings, in particular the PSEs, should therefore be interpreted with caution.

# Part 2. Population size estimates

## 2.1 Assumptions of the Multiplier Method were not met

Population size estimates were calculated using the Multiplier Method (for details, see 'Population Size Estimate method: Multiplier Methods'). The Multiplier Method relies on several key assumptions to produce valid results. If these assumptions are not met, the accuracy and reliability of the PSEs can be significantly compromised. The key assumptions of the MM are that the benchmark data is accurate, that the population is relatively stable, and that the study sample is sufficiently representative of the population as a whole (Hickman & Taylor, 2005).

In OPAAK, the assumptions of the Multiplier Method were not fully met, introducing uncertainty into the PSE calculations. As a result, the estimates should be interpreted with caution. Below, we explain how our data deviates from the assumptions and the potential implications.

Assumption #1: Accuracy of benchmark data
The LADIS benchmark is not accurate, as outlined in Chapter 1. This is due to incomplete reporting and underreporting of data to LADIS. In addition to that, the crack cocaine population is especially inaccurate in LADIS due to limited specification between powder cocaine and crack cocaine (see Chapter 1 for a more detailed explanation).

Assumption #2: Stability of a population
We cannot assume that the HRCCU-only population is currently stable. The stability of a population refers to the number of individuals entering or exiting from the population over the study period (Hickman & Taylor, 2005). While this number is typically considered negligible in practical terms, it is a factor worth mentioning here, as experts in the field have been observing an increase in crack cocaine users in the past 1-3 years.

Assumption #3: Representativeness of the study sample
We cannot be certain that the study sample is representative of the overall population for a number of reasons. First, as discussed in Chapter 1, the overview of in-LADIS locations used for recruitment may have been incomplete. Any gaps in this overview could impact the accuracy (representativeness) of the in-LADIS rate. Second, as detailed in 'Part 1. Recruitment', field workers faced challenges during recruitment that may have limited the representativeness of the sample. Third, the target groups were particularly dynamic during the recruitment period (see 'Part 1. Recruitment'). Fourth, the representativeness of the field sample may be limited due to potential differences between the field sample and the benchmark. Certain groups, such as migrants or non-Dutch speakers, may face barriers to accessing care and could be overrepresented in the field sample compared to the benchmark. Conversely, individuals with stable lifestyles are less likely to be found in the field sample. If the field sample differs significantly from the treatment sample, this could distort the PSE. The more the field sample differs from the treatment sample – in terms of the likelihood that HROU individuals in treatment can also be found among HROU individuals in the field - the Multiplier Method will become less appropriate as a means to estimate a population size of HROU.

## 2.2 In-LADIS rates

To calculate the in-LADIS rate for the PSE, participants were asked about their use of addiction care services that report data to LADIS (see Chapter 1 for details on the methodology). Overall, 52.8% (n=199) of participants reported using at least one such service in the past year. However, significant differences were observed between groups: 61.1% of HROU participants had accessed addiction care services in 2023, compared to just 30.7% of HRCCU-only participants. Table 1 provides a breakdown of the in-LADIS rates by target group and recruitment city. Across all cities except Den Haag, the in-LADIS rate was lower for HRCCU-only than for HROU participants. Differences in in-LADIS-rates across cities do not necessarily correlate with difficulties in recruitment. For example, Eindhoven and Rotterdam were associated with the most recruitment challenges, but not necessarily the lowest in-LADIS rates.

As LADIS does not contain a complete registration of addiction care in the Netherlands (the gaps are described in Chapter 1), the in-LADIS rate has somewhat limited reliability. Despite this limitation, the data suggests that fewer HRCCU-only individuals received addiction care in 2023 compared to HROU individuals.

Table 1. Unweighted and weighted in-LADIS rates per city and per target group for 2023

| City | HROU (%) | HRCCU-only (%) | Total sample (%) |
|---|---|---|---|
| Amsterdam | 65.2 | 15.6 | 54.4 |
| Rotterdam | 57.0 | 37.5 | 52.4 |
| Den Haag | 36.2 | 44.4 | 38.5 |
| Utrecht | 63.4 | 20.0 | 54.9 |
| Eindhoven | 64.3 | 14.3 | 47.6 |
| Haarlem | 75.0 | 55.6 | 67.4 |
| Groningen | 80.4 | 16.7 | 67.2 |
| Heerlen | 43.5 | 33.3 | 41.4 |
| | | | |
| Unweighted average | 60.6 | 29.7 | 52.8 |
| **Weighted average** | **61.1** | **30.7** | **/** |

Note: The weighted averages were calculated separately for the HROU group and the HRCCU-only group. The weighting was determined by multiplying the percentage of in-LADIS responses per city by the number of respondents in that city within each group. The sum of these weighted values was then divided by the total number of respondents in the respective group.

The proportion of people accessing addiction care, as indicated by the in-LADIS rate, appears to have decreased for both groups compared to over a decade ago (see Table 2). For people with HROU, the in-LADIS rate decreased from 87% in 2008 to 61.1% in 2023. For people with HRCCU-only, the rate declined from 41% to 30.7%. It should be noted that this is based on the assumption that the representativeness of the field samples is comparable across the three studies.
According to IVZ, the institutions that provide addiction care to HROU and HRCCU-only individuals and that report data to LADIS have remained stable over time (J. Wisselink, personal communication, September 2024). Therefore, the observed decline in the in-LADIS rate is unlikely due to a reduction in reporting institutes. Possible reasons for the lower in-LADIS rates are proposed in the general discussion.

Table 2. In-LADIS rate per target group in 2023 compared to 2012 and 2008

| Year of data collection | HROU (95% CI) | HRCCU-only (95% CI) |
|---|---|---|
| **2023** (OPAAK, 2025) | 61.1% (56.1% - 65.9%) (weighted) | 30.7% (22.8% - 39.5%) (weighted) |
| **2012** (Cruts et al., 2013) | 79.2% (weighted) | N/A |
| **2008** (Cruts & Van Laar, 2010) | 87% | 41% |

Comparing in-LADIS rates of HROU individuals per city between the current study and the 2012 study shows that while the rates remained the same for Amsterdam (65.0% in 2012), it decreased for Rotterdam (70.0%), Utrecht (80.3%), Eindhoven (87.1%), and Haarlem (83.3%)[8].

[8] Only these five cities were included in the 2012 study.

## 2.3 Population size estimate of people with HROU

Initial calculation

The population size of people with HROU was estimated using the Multiplier Method (for details, see Methods in Chapter 2). The benchmark was based on the number of people with HROU in LADIS in 2023, which was 9630[9]. For the multiplier, we used the inverse of the weighted average in-LADIS rate for people with HROU, as identified during the fieldwork study (July 2023-July 2024): 100/61.1. Confidence intervals for the PSEs were derived by applying the lower and upper bounds of the in-LADIS rates to the formula, reflecting the uncertainty in the multiplier values.

We applied the formula for the Multiplier Method:

Benchmark x Multiplier = Total

HROU PSE 2023:

9630 x (100/61.1) = 15,761 (95% CI: 14,613 – 17,166)

Correction

The Multiplier Method is based on the assumption that the study sample is representative of the population. However, based on expert opinion, we expect individuals in the field to differ somewhat from the population as a whole. The HROU population consists of individuals who might be considered 'more problematic' and 'less problematic', with the latter having a more stable lifestyle (e.g., stable housing, less procurement crime, less contact with the police). The group of 'less problematic' individuals are less likely to be identified in a field study, as they typically spend less time on the streets or in harm reduction facilities. Therefore, a correction factor should be applied to the Multiplier Method in order to not overestimate the size of the population.

*Correction in the 2012 study:*
In the 2008 PSE study in the Netherlands, it was estimated that 60% of HROU individuals in LADIS were 'more problematic'. The 2012 PSE study used the same proportion, such that: of the 12,313 people with HROU in LADIS, 7388 (60%) were considered 'more problematic' and 4925 (40%) were considered 'less problematic'. Based on the assumption, that only 'more problematic' individuals are found in the field study, the multiplier (based on the weighted in-LADIS rate of 79.2%) was applied to the 'more problematic' subgroup. Using this correction, the PSE for people with HROU was 14,253.

| |
|---|
| 12,313 HROU = 7388 more problematic (60%) + 4925 less problematic (40%) |
| (100/79.2) x 7388 + 4924 = **14,253 (HROU PSE in 2012)** |

*Correction in the 2023 study:*
For congruency in the methodology, we applied the same correction factor to the present data[10]. Of the 9630 people with HROU in LADIS in 2023, 5778 (60%) were considered 'more problematic' and 3852 (40%) were 'less problematic'. The multiplier (based on the weighted in-LADIS rate 61.1%) was applied to the 'more problematic' subgroup. Using this correction, the PSE for people with HROU is approximately 13,300 (95% CI: 12,600 – 14,200).

| |
|---|
| 9630 HROU = 5778 more problematic (60%) + 3852 less problematic (40%) |
| (100/61.1) x 5778 + 3852 = **13,309 (95% CI: 12,622 – 14,153) (HROU PSE in 2023)** |

[9] This number differs slightly from the one reported in the annual LADIS report (J. Wisselink, personal communication, December 2024).
[10] While experts have no insight into the current proportion of 'more' or 'less' problematic individuals in LADIS, they agreed that applying the proportion from the previous studies is a best educated guess to improve current estimates.

Possible range due to different in-LADIS rates across cities

The proportion of HROU individuals assessing addiction care in the past year varied by city. The Hague had the lowest in-LADIS rate at 36.2%, while Groningen had the highest at 80.4%. By using these extremes, we could have calculated the outer ranges for the PSE. However, to obtain a less extreme and more plausible range, we used the second to lowest in-LADIS rate (43.5% in Heerlen) and the second to highest in-LADIS rate (75.0% in Haarlem) for our calculations. These figures offer additional insight into the potential extremes of the PSE range.

| |
|---|
| (100/43.5) x 5778 + 3852 = 17,135 (highest range HROU PSE) |
| (100/75.0) x 5778 + 3852 = 11,556 (lowest range HROU PSE) |

Prevalence rate per 1,000

The European Union Drugs Agency (EUDA) compares high-risk drug use across European countries using prevalence rates per 1,000 inhabitants aged 15-64. In 2023, the Netherlands had a population of 11,477,000 in this age group. Based on the 2023 HROU PSE, the prevalence of HROU in the Netherlands was 1.16 (range: 1.10 – 1.24) per 1,000 inhabitants.

| | |
|---|---|
| Central rate/1,000 (age 15-64) | (13,300 HROU / 11,477,000 total) x 1,000 = **1.16** |
| Lower rate/1,000 (age 15-64) | (12,600 HROU / 11,477,000 total) x 1,000 = **1.10** |
| Upper rate/1,000 (age 15-64) | (14,200 HROU / 11,477,000 total) x 1,000 = **1.24** |

## 2.4 Population size estimate of people with HRCCU-only

Initial calculation

The population size of people with HRCCU-only was estimated using the Multiplier Method (for details, see Methods in Chapter 2). The benchmark was based on the number of people with HRCCU-only in LADIS in 2023, which was 1262[11]. For the multiplier, we used the inverse of the weighted average in-LADIS rate for people with HRCCU-only, as identified during the fieldwork study (July 2023-July 2024): 100/30.7. Confidence intervals for the PSEs were derived by applying the lower and upper bounds of the in-LADIS rates to the formula, reflecting the uncertainty in the multiplier values. As the PSE of HRCCU-only is based on a small sample size of around 100 rather than approximately 400, it is considered a preliminary PSE with limited reliability.

We applied the formula for the Multiplier Method:

Benchmark x Multiplier = Total

HRCCU-only preliminary PSE 2023:

1262 x (100/30.7) = 4,111 (95% CI: 3,195 – 5,535)

Correction

The Multiplier Method is based on the assumption that the benchmark is accurate. However, as outlined in Chapter 1, LADIS is not an accurate benchmark, and the crack cocaine data in LADIS is especially incomplete. When service providers select the category 'cocaine' in the registration system, they often fail to specify whether the client snorts or smokes cocaine, indicating cocaine compared to crack cocaine use (J. Wisselink, personal communication, October 2024). As a result, many patients using crack cocaine are grouped under the

[11] This number differs slightly from the one reported in the annual LADIS report; J. Wisselink, personal communication, December 2024.

category 'cocaine unspecified', making the crack cocaine group appear smaller than it is. Therefore, the 1262 HRCCU-only clients in LADIS are an underrepresentation and the PSE of 4111 is an underestimation.

For comparison, in 2008, there were 5086 clients in LADIS with cocaine listed as their primary, secondary or tertiary substance of dependence[12]. Based on an in-LADIS rate of 41% in 2008, the population size for HRCCU-only individuals was estimated to be 12,400 (95% CI: 10,300 – 15,600) (Cruts & Van Laar, 2010). It should be noted that the 2008 estimate was based on a small sample size, limiting the reliability of the PSE.

| |
|---|
| (100/41.0) x 5086 = **12,405 (HRCCU-only PSE in 2008)** |

*Correction in the 2023 study:*
To correct for the underestimation, two correction factors were applied, including an adjustment of the benchmark and a stratification of the multiplier.

*#1. Benchmark adjustment:* We extrapolated the data from the group 'cocaine unspecified' using the known proportion of cocaine and crack cocaine users in LADIS. This was done for people with 'cocaine' (the broader category) as their primary and secondary substance of dependence. (Route of administration is not recorded for cocaine as a tertiary substances.) In 2023, the known proportion of people in LADIS using crack cocaine as their primary substance of dependence was 40%. When applying the 40% to clients with 'cocaine unspecified' and adding the known proportion of crack cocaine clients, this yields a total of 3235 individuals. The same approach was applied to individuals with crack cocaine as a secondary substance of dependence, yielding a total of 2168 individuals. Together that makes a total of 5403 people with high-risk crack cocaine use in LADIS.

'Cocaine' as someone's primary or secondary substance of dependence in 2023 in LADIS

| | Powdered cocaine | Crack cocaine | Cocaine unspecified | Proportion powdered cocaine | Proportion crack cocaine | Extrapolated crack cocaine | **Total crack cocaine** |
|---|---|---|---|---|---|---|---|
| Primary | 2238 | 1519 | 4289 | 60% | 40% | 0.4 x 4289 = 1716 | 1519 + 1716 = **3235** |
| Secondary | 3664 | 1861 | 902 | 66% | 34% | 0.34 x 902 = 307 | 1861 + 307 = **2168** |

Based on this adjusted benchmark (5403 HRCCU-only individuals) and the weighted in-LADIS rate (30.7%), the PSE for people with HRCCU-only would be approximately 17,600 (95% CI: 13,700 – 23,700).

*#2. Stratification of the multiplier:* Descriptive data presented in Chapter 2, Part 3, shows that, among the total sample, the in-LADIS rate differed between people born in the Netherlands (62% in LADIS) compared to those not born in the Netherlands (46% in LADIS). Moreover, among HRCCU-only individuals, the proportion born in the Netherlands differed strongly between the LADIS population (73.0%) and the field sample (36.2%). If the in-LADIS rate differs strongly for these groups (in LADIS versus field sample), but a single in-LADIS rate is used for the whole population, this could distort the PSE. To address this, we stratified the data by country of birth to generate a more accurate estimate.

Proportion of participants born in the Netherlands

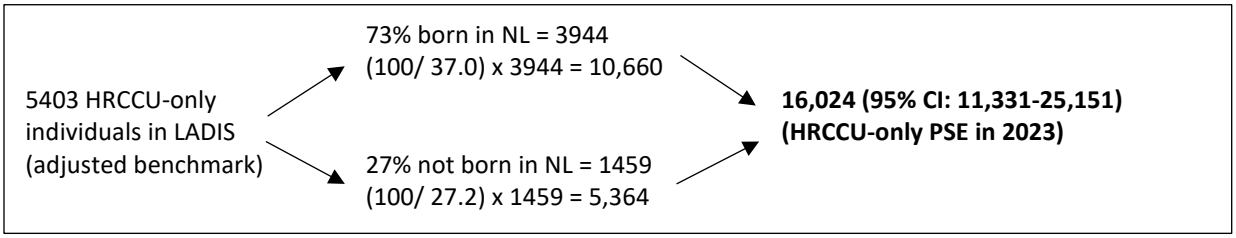
| | In LADIS | OPAAK field sample |
|---|---|---|
| HROU | 65.7% | 52.7% |
| HRCCU-only | 73.0% | 36.2% |

- *Step 2.1: Benchmark stratified by country of birth.* In 2023, in LADIS, 829 out of 1136 HRCCU-only individuals (73.0%) were born in the Netherlands. Applying this proportion to the adjusted benchmark

[12] This number refers to people using crack cocaine and not necessarily the HRCCU-only population in LADIS.

of 5403 HRCCU-only individuals in LADIS, this yields 3944 patients born in the Netherlands (73.0%) and 1459 patients not born in the Netherlands (27.0%).

- *Step 2.2: in-LADIS rates stratified by country of birth.* Among HRCCU-only individuals, those born in the Netherlands had an in-LADIS rate of 37.0%, compared to 27.2% for those not born in the Netherlands. Confidence intervals for the PSE were derived by applying the lower and upper bounds of the in-LADIS rates to the formula, reflecting the uncertainty in the multiplier values. Based on the adjusted benchmark and stratified multiplier, the HRCCU-only PSE is about 16,000 (95% CI: 11,300 – 25,200).




Possible range due to different in-LADIS rates across cities

The proportion of HRCCU-only individuals accessing addiction care in the past year varied by city. Eindhoven had the lowest in-LADIS rate at 14.3%, while Haarlem had the highest in-LADIS rate at 55.6%. By using these extremes, we could have calculated the outer ranges for the PSE. However, to obtain a less extreme and more plausible range, we used the second to lowest in-LADIS rate (15.6% in Amsterdam) and the second to highest in-LADIS rate (44.4% in The Hague) for our calculations. These figures offer additional insight into the potential extremes of the PSE range.

(100/15.6) x 5403 = 34,634 (highest range)

(100/44.4) x 5403 = 12,169 (lowest range)

Total population of crack cocaine users

It is important to note that the HRCCU-only PSE excludes people who use both crack cocaine and opioids, as these are included in the HROU group in this study. Below we provide a rough estimate of the total population of crack users:

Of the 393 HROU participants, 351 also reported high-risk crack cocaine use (HRCCU). That means 89.3% of HROU also engaged in HRCCU. If we apply this percentage to the estimated HROU population of 13,300, we find that 11,877 of those individuals are also high-risk crack cocaine users. When adding those individuals to the HRCCU-only population, we obtain a total population of around 27,900 crack users (with and without concurrent opioid use).

351 HROU+HRCCU / 393 HROU = 89.3% of HROU participants also engaged in HRCCU

89.3% x 13,300 HROU PSE = 11,877 estimated people with HROU and HRCCU

16,024 HRCCU-only PSE + 11,877 HROU+HRCCU PSE = **27,901 people with HRCCU in 2023**

Prevalence rate per 1,000

The European Union Drugs Agency (EUDA) compares high-risk drug use across European countries using prevalence rates per 1,000 inhabitants aged 15-64. In 2023, the Netherlands had a population of 11,477,000 in this age group. Based on the 2023 HRCCU-only PSE, the prevalence of HRCCU-only in the Netherlands was 1.39 (range: 1.00 – 2.20) per 1,000 inhabitants.

| | |
|---|---|
| Central rate/1,000 (age 15-64) | (16,000 HRCCU-only / 11,477,000 total) x 1,000 = **1.39** |
| Lower rate/1,000 (age 15-64) | (11,300 HRCCU-only / 11,477,000 total) x 1,000 = **1.00** |
| Upper rate/1,000 (age 15-64) | (25,200 HRCCU-only / 11,477,000 total) x 1,000 = **2.20** |

## 2.5 Conclusions

The 2023 PSE of people with HROU was **13,300 (95% CI: 12,600 – 14,200)**, which is lower than the 2012 estimate of 14,300 (13,400 – 16,300). However, the overlapping confidence intervals suggest that this difference may not be statistically significant.

The 2023 preliminary PSE of people with HRCCU-only was estimated to be **16,000 (95% CI: 11,300 – 25,200)**. This appears to be an increase from the 2008 estimate of 12,400 (10,300 – 15,600). It is important to note that this estimate excludes 'dual users' who engage in high-risk use of both opioids and crack cocaine. The total population of people with HRCCU (with and without concurrent opioid use) is estimated to be around 27,900.

Prevalence rates per 1,000 inhabitants aged 15-64 were 1.16 (1.10 – 1.24) for the HROU population and 1.39 (1.00 – 2.20) for the HRCCU-only population in 2023.

The estimates need to be interpreted with caution given that the assumptions of the Multiplier Method were not fully met. This is primarily due to challenges with the registration of addiction care and issues during the field work which may have biased the sample.

## Part 3. Descriptive characteristics of people with HROU and HRCCU-only

The present study examined not only the size but also the characteristics of the populations of people with HROU and HRCCU-only. In this section we describe the sample composition and whether recruitment targets were met, followed by an analysis of variables, including service use, substance use patterns, injection drug use and risk behaviour, physical and mental health, treatment experiences, and quality of life. We compare the two groups to identify potential differences between them. This comprehensive assessment provides valuable insights into the characteristics and experiences of individuals with HROU and HRCCU-only, highlighting their needs and challenges. These findings can be used to inform targeted interventions and policy development to help improve health, wellbeing, and access to care.

### 3.1 Participant distribution across recruitment cities

Our recruitment target was to enrol 374 people with HROU for a reliable PSE, and 100 people with HRCCU-only for a preliminary PSE. We successfully recruited 393 and 127 participants, respectively. Table 3 presents the distribution of participants and their demographic characteristics across the eight recruitment cities and overall. Table 4 compares the target distribution of participants with the achieved distribution for each target group. For details on the sampling targets, see 'Sampling method and recruitment strategy' in the Methods section of Chapter 2.

The target distribution across cities was largely achieved, with the exception of Eindhoven and Rotterdam. In Rotterdam, we recruited 19.8% of participants instead of the target 24.0%, and in Eindhoven, we recruited 4.0% instead of the target 7.0% (see Table 3 and Table 4). Instead we recruited more participants in Amsterdam. (Challenges faced in each city are discussed in 'Part 1. Recruitment'). We successfully met our gender distribution target of recruiting between 82% and 86% men. Across all cities, 85.1% were men, ranging from 78.4% to 91.3%. The mean age of participants was 50.0 years, with a range of 46.7 to 53.7 years across cities. Overall, the data reflects a balanced study sample across cities, closely aligning with our target distributions.

Table 3. Participant distribution and demographic characteristics across recruitment cities

| City | n | % | Mean Age (Range) | Male (%) | Female (%) | Other (%) |
|---|---|---|---|---|---|---|
| Amsterdam | 147 | 28.3 | 51.7 (21-77) | 84.3 | 15.1 | 0.7 |
| Rotterdam | 103 | 19.8 | 47.8 (26-69) | 83.0 | 17.0 | 0.0 |
| Den Haag | 65 | 12.5 | 49.8 (24-79) | 89.2 | 9.2 | 1.5 |
| Utrecht | 51 | 9.8 | 48.0 (19-66) | 78.4 | 21.6 | 0.0 |
| Eindhoven | 21 | 4.0 | 49.9 (26-66) | 81.0 | 14.3 | 4.8 |
| Haarlem | 46 | 8.9 | 46.7 (23-66) | 91.3 | 8.7 | 0.0 |
| Groningen | 58 | 11.2 | 53.7 (35-73) | 87.9 | 12.1 | 0.0 |
| Heerlen | 29 | 5.6 | 50.4 (33-67) | 86.2 | 13.8 | 0.0 |
| **Total** | **520** | **100.0** | **50.0 (19-79)** | **85.1** | **14.3** | **0.6** |

Note: Data on gender is missing from 1 participant in Amsterdam and from 3 participants in Rotterdam.

Table 4. Distribution of the two target groups across recruitment cities

| City | Target (%) | HROU (%) | HRCCU-only (%) |
|---|---|---|---|
| Amsterdam | 24 | 29.3 | 25.2 |
| Rotterdam | 24 | 20.1 | 18.9 |
| Den Haag | 12 | 12.0 | 14.2 |
| Utrecht | 9 | 10.4 | 7.9 |
| Eindhoven | 7 | 3.6 | 5.5 |
| Haarlem | 7 | 7.1 | 14.2 |
| Groningen | 12 | 11.7 | 9.5 |
| Heerlen | 5 | 5.9 | 4.7 |
| **Total** | **100** | **100** | **100** |

## 3.2 Sample composition

Table 5 summarizes the composition of the study sample, presenting the proportions of different subgroups. Figure 1 provides a visual representation of these subgroups, while Figure 2 highlights the two main target groups for clarification.

Data should be interpreted with caution. As detailed in 'Part 1. Recruitment,' people with HROU and HRCCU-only were identified at similar frequency during recruitment. This suggests that the sample proportions – 75.6% HROU and 24.4% HRCCU-only – likely overestimate the prevalence of HROU relative to HRCCU-only in the population. According to the field workers, the true distribution in the broader population is likely closer to a 50-50 split.

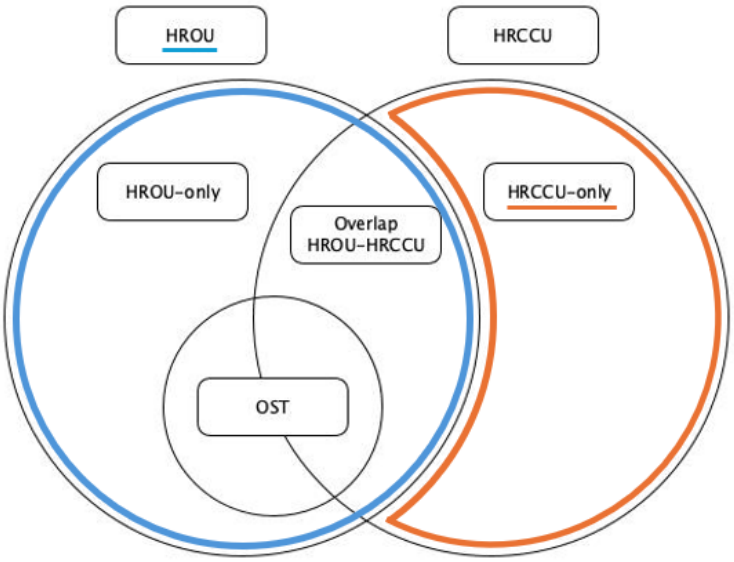
The data shows that 91.9% of all participants reported high-risk use of crack cocaine, while 67.5% reported high risk use of both opioids and crack cocaine. Among participants receiving OAT, all (100%) engaged in high-risk use of crack cocaine, and 27.7% (65/235) no longer engaged in concurrent high-risk use of opioids.

Table 5. Composition of the study sample

| | | Percentage of the total sample (N=520) | |
|---|---|---|---|
| **Subgroups** | **Description** | **n** | **%** |
| **HROU** | **Opioid use and/or in OAT (may also use crack)** | **393** | **75.6** |
| HRCCU | Crack use (may also use opioids or be in OAT) | 478 | 91.9 |
| HROU-only | Opioid use and/or in OAT, but no crack use | 42 | 8.1 |
| **HRCCU-only** | **Crack use, but no opioid use and not in OAT** | **127** | **24.4** |
| Overlap HROU-HRCCU | Opioid use and/or in OAT, and crack use | 351 | 67.5 |
| OAT | In OAT (may also use opioids or crack) | 235 | 45.2 |

Note: 'Opioid use' and 'crack use' are used synonymously to 'high-risk opioid use' and 'high-risk crack cocaine use' to enhance readability of the descriptions. The two main target groups are marked in bold.

Figure 1. Six subgroups in the total sample with the two target groups highlighted for clarification




## 3.3 Sociodemographic characteristics

Sociodemographic characteristics of the two target groups and the total sample are presented in Table 6. In the total sample, most participants were male (85.1%), and slightly more than half (51.3%) were born outside the Netherlands. Mean age was 50.0 years, with the 50-59 age group being the most common (30.8%). Most participants (32.9%) had attained a lower secondary education, and the majority were unfit for work (37.4%) or unemployed (37.6%). Among those employed, 19 individuals reported working an average of 22 hours per week (range 3-40 hours). A significant proportion of participants (39.0%) lived in assisted living facilities, though this may be overrepresented due to frequent recruitment at these sites. Additionally, 22.5% reported sleeping on the streets. Most participants were not in a relationship (78.6%) and fewer than half (48.6%) had children. While the majority (83.8%) had Dutch health insurance, 15.1% lacked any form of health insurance. Finally, 35.4% of participants had both parents born in the Netherlands, 15.6% had at least one parent born in an EU country, and 48.8% had at least one parent born in a non-EU country.

Differences between target groups

Some differences emerged between the target groups. The Chi-square test shows significant differences between the HROU and HRCCU-only groups on age ($\chi^2(4) = 113.4$, $p < 0.001$), country of birth ($\chi^2(1) = 32.49$, $p < 0.001$), and housing (assisted living facility: $\chi^2(1) = 12.12$, $p < 0.001$; homeless shelter/night shelter: $\chi^2(1) = 184.12$, $p < 0.001$). This means that individuals in the HRCCU-only group were younger (mean age 47.8) than those in the HROU group (mean age 50.7). More HRCCU-only participants were born in a non-EU country (52.8%) compared to HROU participants (35.6%). HRCCU-only participants were more likely to reside in homeless shelters/night shelters (22.1%) than HROU participants (15.8%) and less likely to stay in assisted living facilities (32.3%) than HROU individuals (41.2%). Small differences between groups in other variables might be more pronounced if the HRCCU-only sample was as large as the HROU sample.

Table 6. Sociodemographic characteristics of the HROU and HRCCU-only groups and overall

| | **HROU** (n=393) | **HRCCU-only** (n=127) | **Total sample** (N=520) |
|---|---|---|---|
| **Sociodemographic data** | **% or Mean** | **% or Mean** | **% or Mean** |
| Gender | | | |
| - Male | 84.6 | 86.6 | 85.1 |
| - Female | 14.7 | 13.4 | 14.3 |

| | | | |
|---|---|---|---|
| - Other | 0.8 | 0 | 0.6 |
| Age | | | |
| - 18 – 29 | 2.3 | 5.5 | 3.1 |
| - 30 – 39 | 13.5 | 15.8 | 14.0 |
| - 40 – 49 | 28.2 | 33.1 | 29.4 |
| - 50 – 59 | 31.6 | 28.4 | 30.8 |
| - 60+ | 24.4 | 17.3 | 22.7 |
| Mean age (years) | 50.7 (19 - 79) | 47.8 (21 - 67) | 50.0 (19 - 79) |
| Country of birth | | | |
| - The Netherlands | 52.7 | 36.2 | 48.7 |
| - Another EU country | 11.7 | 11.0 | 11.5 |
| - A non-EU country [1] | 35.6 | 52.8 | 39.8 |
| Country of birth of parents | | | |
| - Both parents born in the Netherlands | 38.4 | 26.0 | 35.4 |
| - One or both parents born in the EU | 16.3 | 13.4 | 15.6 |
| - One or both parents born in a non-EU country | 45.0 | 60.6 | 48.8 |
| Highest attained level of education | | | |
| - Primary education or no education | 32.1 | 25.2 | 30.4 |
| - Lower secondary education | 31.8 | 36.2 | 32.9 |
| - Higher secondary education | 27.5 | 32.3 | 28.7 |
| - Bachelor's degree | 7.1 | 4.7 | 6.5 |
| - Master's degree or higher | 1.5 | 1.6 | 1.5 |
| Employment | | | |
| - Paid work | 5.1 | 3.2 | 4.6 |
| - Voluntary work/internship | 16.6 | 18.9 | 17.2 |
| - Retired | 3.3 | 3.2 | 3.3 |
| - Unfit for work | 36.5 | 40.2 | 37.4 |
| - Unemployed | 38.5 | 34.7 | 37.6 |
| Housing | | | |
| - Rent or own an accommodation | 17.8 | 18.1 | 17.9 |
| - Staying with family or friends | 2.0 | 3.9 | 2.5 |
| - Assisted living facility | 41.2 | 32.3 | 39.0 |
| - Homeless shelter/ night shelter | 15.8 | 22.1 | 17.3 |
| - On the street | 22.4 | 22.8 | 22.5 |
| - Other | 0.8 | 0.8 | 0.8 |
| Relationship | | | |
| - Yes, living together | 4.3 | 1.6 | 3.7 |
| - Yes, living separately | 17.6 | 18.1 | 17.7 |
| - No | 78.1 | 80.3 | 78.6 |
| Children | | | |
| - Yes | 48.3 | 49.6 | 48.6 |
| - No | 51.7 | 50.4 | 51.4 |
| Health insurance | | | |
| - Dutch health insurance | 83.1 | 85.8 | 83.8 |
| - Non-Dutch health insurance | 1.5 | 0 | 1.2 |
| - No health insurance | 15.4 | 14.2 | 15.1 |

Note: The number of respondents from the total sample ranges from 516 to 520 across these items.

[1] Participants born in non-EU countries include a high number of individuals from Suriname (n=56), Morocco (n=39), Curacao (n=18), and Algeria (n=11).

Participants born in non-EU countries were asked about their residence status in the Netherlands. Of the 186 respondents, 87.1% had a residence permit, 1.1% were asylum seekers, and 11.8% were undocumented (see Table 7).

Table 7. Residence permit among participants born in a non-EU country

| | **HROU** (n=124) | **HRCCU-only** (n=62) | **Total sample** (N=186) |
|---|---|---|---|
| | **%** | **%** | **%** |
| Residence permit | | | |
| - Yes | 83.9 | 93.6 | 87.1 |
| - No, asylum seeker | 1.6 | 0.0 | 1.1 |
| - No, undocumented | 14.5 | 6.5 | 11.8 |

## 3.4 Service use

Participants were asked about their use of different types of services over the past 12 months. Nearly all participants (98.3%, n=511) reported using at least one service during this period. The most commonly used services were walk-in/drop-in centre and doctor or nurse visits, each reported by 71.9% of participants (see Table 8). Service use patterns were largely similar between the HROU and HRCCU-only groups, with one notable exception: drug consumption rooms. A higher proportion of HROU participants (45.9%) reported using drug consumption rooms in the past year, compared to 30.7% of HRCCU-only participants.

Table 8. Service use in the past 12 months

| **Services** | **HROU (% Yes)** | **HRCCU-only (% Yes)** | **Total sample (% Yes)** |
|---|---|---|---|
| Opioid agonist therapy | 62.1 | N/A* | 47.9 |
| Drug consumption room | 45.9 | 30.7 | 42.2 |
| Needle and syringe exchange | 9.0 | 0.0 | 6.8 |
| Walk-in/ Drop-in centre | 73.2 | 67.7 | 71.9 |
| Night shelter | 35.1 | 37.0 | 35.6 |
| Help with housing | 47.3 | 42.1 | 46.1 |
| Budget management/ debt counselling | 62.5 | 67.5 | 63.7 |
| Doctor or nurse | 72.5 | 70.1 | 71.9 |
| Social worker | 54.1 | 58.3 | 55.1 |
| Psychological help (e.g. therapist, psychologist, psychiatrist) | 21.7 | 27.6 | 23.2 |
| Other support (e.g. case manager, buddy) | 18.7 | 15.8 | 18.0 |

Note: The number of respondents from the total sample ranges from 516 to 520 across these items. This list includes any services regardless of whether they report data to LADIS or not.
*N/A = Not applicable. Individuals with HRCCU-only are by definition not in opioid agonist therapy (see 'Case definitions').

## 3.5 Substance use

This section examines patterns of non-prescribed substance use among the target groups. We analysed substances use in the past 12 months, with a particular focus on different opioid types, to determine whether

synthetic opioids are emerging on the Dutch market, as observed in other European countries. Frequency of use and routes of administration were explored, with a focus on injection drug use due to its implication for health risks. We also investigated the age of initiation for opioid and crack cocaine use – a metric reported by the European Drugs Agency – to understand early exposure patterns. Lastly, we assessed the history of opioid use and OAT within the HRCCU-only group to determine if this group represents a distinct population or is comprised of individuals who transitioned from opioid to crack cocaine use.

### 3.5.1 Non-prescribed substance use in the past 12 months

Participants reported which non-prescribed substances they had used at least once in the past 12 months. Overall, the two groups exhibited similar substance use patterns, with one notable exception: benzodiazepine use was more prevalent among people with HROU (26.0%) than those with HRCCU-only (12.7%). Moreover, it is worth noting that even though HRCCU-only individuals do not engage in high-risk use of opioids (i.e. weekly use), some still used opioids at least once in the past year.

In the total sample, the vast majority (96.0%) reported using crack cocaine in the past year. Other commonly reported substances included cannabis (76.5%) and alcohol (66.2%), followed by amphetamines (29.5%), cocaine (28.1%), benzodiazepines (22.9%), and psychedelics (21.4%) (see Table 9). Substances mentioned in the open-ended 'Other' category covered a wide range, including New Psychoactive Substances (e.g., 4-MMC) and non-prescribed medications (e.g., Valium). Several participants indicated using 'designer drugs' but were unsure of the specific substances.

Table 9. Non-prescribed substance use in the past 12 months

| Substances | HROU (% Yes) | HRCCU-only (% Yes) | Total sample (% Yes) |
|---|---|---|---|
| Opioids | 85.4% | 17.6% | 69.4% |
| Crack cocaine | 94.8% | 100% | 96.0% |
| Cocaine | 26.0% | 34.9% | 28.1% |
| Amphetamine | 28.6% | 32.5% | 29.6% |
| Methamphetamine | 8.4% | 3.2% | 7.2% |
| Benzodiazepines | 26.0% | 12.7% | 22.9% |
| Ketamine | 13.3% | 12.7% | 13.1% |
| GHB/GBL | 11.0% | 9.5% | 10.7% |
| Psychedelics (e.g. MDMA, LSD) | 21.4% | 21.5% | 21.4% |
| Cannabis | 75.0% | 80.6% | 76.5% |
| Alcohol | 64.5% | 71.2% | 66.2% |
| Alpha-PVP | 2.1% | 0.0% | 1.6% |
| 3-MMC of 3-CMC | 4.4% | 6.4% | 4.8% |
| Other substances | 4.8% | 5.0% | 4.9% |

Note: The number of respondents from the total sample ranges from 494 to 519 across these items.
Note: Opioid use is not 100% for the HROU group, because some individuals may be in OAT but no longer actively use non-prescribed opioids. Opioid use is not 0% for the HRCCU-only group because even though they do not engage in high-risk opioid use, they may use opioids infrequently (i.e. at least once in the past year).

Participants were also asked to specify which non-prescribed opioids they used at least once in the past 12 months. Among HROU individuals, heroin was the most commonly reported opioid (82.5%) followed by methadone (44.4%), while the use of other synthetic opioids was lower (see Table 10). However, these findings should be interpreted with caution. Although participants were explicitly asked about *non-prescribed* opioid use, it is unclear whether all reported methadone use involved diverted methadone. Some individuals may have reported methadone use because they receive it as OAT. This misunderstanding was also noted as an issue in the previous PSE study in the Netherlands (Cruts et al. 2013). Interestingly, even though HRCCU-only individuals do not use opioids on a weekly basis, some had used opioids at least once in the past year.

Table 10. Non-prescribed opioid use in the past 12 months

| Non-prescribed opioids | HROU (% Yes) | HRCCU-only (% Yes) |
|---|---|---|
| Heroin | 82.5% | 15.1% |
| Methadone | 44.4% | 5.9% |
| Buprenorphine | 2.9% | 0.8% |
| Oxycodone | 6.5% | 1.7% |
| Tramadol | 8.1% | 1.7% |
| Fentanyl or carfentanil | 3.7% | 1.7% |
| Other opioids | 1.0% | 0.8% |

Note: The number of respondents from the total sample ranges from 500 to 502 across these items.

### 3.5.2 Frequency of substance use in the past month

Table 11 shows the average frequency of substance use in the past month among individuals who reported using that substance during that period. Crack cocaine, cannabis, opioids and alcohol were the most frequently used substances, averaging 23, 21, 20, and 16 days per month, respectively. Although other substances were used far less frequently, it is still worth noting that individuals reported using a wide variety of substances within the past month.

Table 11. Frequency of substance use in the past month

| Substances | Mean number of days per month | Interquartile Range Q1-Q3 | n* |
|---|---|---|---|
| Opioids | 20 days | 9-30 | 321 |
| Crack cocaine | 23 days | 15-30 | 474 |
| Cocaine | 5 days | 1-4 | 96 |
| Amphetamine | 8 days | 1-12 | 102 |
| Methamphetamine | 2 days | 1-2 | 23 |
| Benzodiazepines | 10 days | 1-17 | 87 |
| Ketamine | 3 days | 1-2 | 31 |
| GHB/GBL | 3 days | 1-2 | 21 |
| Psychedelics (e.g. MDMA, LSD) | 2 days | 1-3 | 74 |
| Cannabis | 21 days | 10-30 | 367 |
| Alcohol | 16 days | 4-30 | 290 |
| Alpha-PVP | 3 days | 2-4 | 2 |
| 3-MMC/3-CMC | 2 days | 1-1 | 12 |

*N's are based on participants who used the specific substance (i.e. non-zero values) and non-missing data.
Note: The range of values is 1 – 30 days for most substances, except: 1-13 days for methamphetamine, 1-20 days for GHB/GBL, 1-26 days for Psychedelics, 2-4 days for alpha-PVP, and 1-13 days for 3-MMC/3-CMC.

### 3.5.3 Route of administration in the past month

We examined the routes of administration (ROA) for four substances: opioids and crack cocaine (the primary focus of this study), and methamphetamine and 3-MMC, due to indications that these substances are occasionally injected by certain subgroups in the Netherlands (T. Van Dijk, personal communication, June 2023). Overall, past-month injection rates were relatively low across all four substances, ranging from 3.2% to 9.1% (see Table 12). Methamphetamine had the highest injection rate (9.1%) followed by opioids (7.6%).

Findings should be interpreted with caution due to the small sample size for some substances such as methamphetamine. In contrast, the majority of participants reported smoking or inhaling opioids, crack cocaine, and methamphetamine (84.9% - 99.4%). For 3-MMC, snorting was the most commonly reported method (70.8%).

Table 12. Past-month route of administration of four substances

| | **Opioids** (n=344) | **Crack cocaine** (n=497) | **Methamphetamine** (n=33) | **3-MMC** (n=24) |
|---|---|---|---|---|
| Injected | 7.6% | 3.2% | 9.1% | 4.2% |
| Smoked/inhaled | 93.6% | 99.4% | 84.9% | 12.5% |
| Snorted | 2.9% | 0.8% | 3.0% | 70.8% |
| Swallowed/drank | 14.0% | 0% | 9.1% | 12.5% |
| Other | 0.3% | 0% | 0% | 8.3% |

Note: Multiple answers were possible.

#### 3.5.4 Age of onset for opioid and crack cocaine use

Participants who reported current HROU and HRCCU were asked about the age at which they first used opioids and crack cocaine, respectively. The average age of first opioid use was 24.2 years (median: 22, range: 12-67, IQR Q1-Q3: 17-30, n=370). For crack cocaine, the average starting age was 26.2 years (median: 25, range: 12-68, IQR Q1-Q3: 19-31, n=451).

#### 3.5.5 History of opioid use and OAT among HRCCU-only participants

To assess whether individuals in the HRCCU-only group had transitioned from opioid use to crack cocaine or represented a new, distinct user population, participants were asked about their past opioid use and experience with OAT. Among respondents from the HRCCU-only group (n=97), 75.3% had never used opioids regularly[13], and 87.6% had never been in OAT. These findings suggest that the HRCCU-only group primarily consists of individuals without a history of regular opioid use, indicating they represent a distinct population.

## 3.6 Injection drug use and risk behaviour

Participants were surveyed about injection drug use (IDU) and related risk behaviour, such as sharing of drug paraphernalia and Hepatitis C Virus (HCV) and HIV testing. Among respondents (n=514), 9.1% reported IDU in the past 12 months, while 63.8% reported sharing drug paraphernalia other than needles in the past 12 months (see Table 13). No participants from the HRCCU-only group had injected drugs in the past year. Among HROU participants, 47 individuals (12.1%) reported past-year IDU. A Chi-squared test confirmed a statistically significant difference between groups ($\chi^2(1) = 15.37$, $p < 0.001$). Sharing of drug paraphernalia other than needles was slightly higher among HRCCU-only participants (66.4%) than HROU participants (63.0%), but this difference was not statistically significant ($\chi^2(1) = 0.34$, $p = 0.56$).

Table 13. IDU and sharing of drug paraphernalia in the past 12 months

| **Variables (respondents)** | **HROU (% Yes)** | **HRCCU-only (% Yes)** | **Total sample (% Yes)** |
|---|---|---|---|
| Past year IDU (n=514) | 12.1% | 0.0% | 9.1% |
| Past year sharing of drug paraphernalia other than needles (e.g. syringes, filter, cotton, crack pipe, snorting straw) (n=514) | 63.0% | 66.4% | 63.8% |

[13] 'Regular use' was defined as weekly use or more frequently, in line with the EUDA definition of HROU.

Those who reported past-year IDU were asked follow-up questions about needle-sharing, HCV and HIV testing, and their source of clean needles. Only one participant (2.2%) reported past year needle-sharing. Testing rates were relatively low: 44.2% had been tested for HCV and 47.6% for HIV in the past 12 months (see Table 14). Given the low incidence of needle-sharing and the high prevalence of drug paraphernalia-sharing among HRCCU-only participants, it is likely that most paraphernalia-sharing involved non-injection equipment, such as crack pipes.

Thirty-two participants reported the sources from which they obtained clean syringes. Twenty-four individuals (75%) obtained needles from addiction care facilities, 6 from pharmacies, 5 from a friend or acquaintance, 1 from the Internet, and 2 from 'another source'. Multiple responses were possible; 6 participants reported obtaining needles from two sources.

Table 14. Sharing of needles and HCV/HIV testing in the past 12 months among people with past-year IDU

| Variables (respondents) | Among participants with past-year IDU (% Yes) |
|---|---|
| Shared needles in the past year (n=45) | 2.2% |
| Past-year HCV testing (n=43) | 44.2% |
| Past-year HIV testing (n=42) | 47.6% |

## 3.7 Health

As it is challenging to obtain a comprehensive overview of an individual's health using a brief survey, we focused on key physical and mental health symptoms to obtain initial insights into potential areas of interest. Additionally, we examined the prevalence of drug overdoses.

### 3.7.1 Physical health

Participants were asked to report current physical health symptoms, which are common among these target groups, using the modified OTI-HSS. An open-response option was offered to identify additional symptoms. The most frequently reported symptoms were dental issues (60.4%), forgetfulness (51.7%), trouble sleeping (50.1%), and shortness of breath or difficulty breathing (50.0%) (see Table 15). Small differences were observed between the HROU and HRCCU-only groups, with HROU participants more frequently reporting shortness of breath, trouble sleeping, and dental issues.

Table 15. Physical health symptoms

| Physical health symptoms | HROU (% Yes) | HRCCU-only (% Yes) | Total sample (% Yes) |
|---|---|---|---|
| Shortness of breath/ difficulty breathing | 52.8% | 40.8% | 50.0% |
| Persistent cough | 44.5% | 41.8% | 43.9% |
| Chest pains | 24.4% | 21.4% | 23.7% |
| Heart flutters/racing | 26.1% | 30.6% | 27.2% |
| Abscesses/infections from injecting | 7.2% | 1.0% | 5.8% |
| Intestinal problems/ diarrhoea/ constipation | 22.5% | 15.3% | 20.8% |
| Trouble sleeping | 52.5% | 42.3% | 50.1% |
| Teeth problems | 63.1% | 51.6% | 60.4% |
| Forgetting things | 52.5% | 49.0% | 51.7% |
| Other | 25.0% | 18.1% | 23.4% |

Note: The number of respondents from the total sample ranges from 394 to 418 across these items. The OTI-HSS items on health symptom were added to the questionnaire later during the recruitment process, meaning these items were not administered to the first roughly 100 participants.

### 3.7.2 Mental health

Mental health was assessed using the PHQ-2 and GAD-2 tools to screen for depressive disorder and generalized anxiety disorder, respectively (for details on the questionnaire items, see the Methods section of Chapter 2). Only participants who completed both items of a tool were included in the analysis. Among these respondents, 78.8% screened positive for depressive disorder and 74.6% for generalized anxiety disorder (see Table 16). Differences between the HROU and HRCCU-only groups were minimal.

Table 16. Screening for depression and anxiety

| Mental health screening (respondents) | HROU | HRCCU-only | Total sample |
|---|---|---|---|
| Positive screen for depression (PHQ-2) (n=513) | 80.4% | 73.8% | 78.8% |
| Positive screen for general anxiety (GAD-2) (n=512) | 75.1% | 73.0% | 74.6% |

### 3.7.3 Overdoses

Participants were asked if they had experienced an overdose in the past 12 months that caused fear for their life or health. Among respondents (n=494), 6.9% (n=34) reported at least one overdose during this period. For those who provided further details, the median number of overdoses in the past year was 1 (IQR Q1-Q3: 1-2, n=33) and the median number of times they required medical help was also 1 (IQR Q1-Q3: 0-2, n=31). Participants reported overdoses involving various substances, with less than half involving opioids.

## 3.8 Treatment

Information on treatment and patient experiences is essential for the development of policies and interventions. It offers valuable insight into treatment effectiveness, deepens our understanding of patient needs, and highlights opportunities to improve access to care and promote healthcare equity. By evaluating participants' access to and experiences with three types of treatment – opioid agonist therapy (OAT), crack cocaine agonist pharmacotherapy, and mental health treatment – we aim to contribute to these efforts.

### 3.8.1 Opioid agonist therapy

Participants who received OAT (n=235) were asked (non-mandatory) follow-up questions regarding their treatment. Among respondents, the majority used methadone (86.0%) and regularly received their OAT medication as take-home doses (70.1%) (see Table 17). Most obtained their OAT medication from a specialized addiction care doctor (77.9%), while a smaller proportion received it from their general practitioner (20.7%). On average, respondents had been in OAT for 14.5 years. Participants rated various aspects of their OAT experience on a 10-point scale (1=very bad, 10=very good). The lowest ratings were given for the effectiveness of OAT in stopping cravings (mean=6.9) and satisfaction with the prescribing doctor (mean=7.2).

Table 17. Opioid agonist therapy

| | % or mean (range or SD) |
|---|---|
| OAT medication | |
| - Methadone | 86.0% |
| - Buprenorphine | 1.4% |
| - Medical heroin/diamorphine | 8.6% |
| - Other | 4.1% |
| Take home OAT | |
| - Yes, regularly | 70.1% |

| | |
|---|---|
| - No, never | 29.9% |
| Prescriber | |
| - General practitioner | 20.7% |
| - Specialized addiction care doctor or someone else | 77.9% |
| - I don't know | 1.4% |
| Duration in OAT | |
| - Duration in OAT in years | 14.5 (range: 1 - 50) |
| Satisfaction with OAT | |
| - Effectiveness in stopping cravings | 6.9 (SD 2.4) |
| - Ability to function with the medication | 7.8 (SD 1.6) |
| - Satisfaction with the doctor prescribing the medication | 7.2 (SD 2.0) |
| - Satisfaction with the one handing out the medication | 7.6 (SD 1.7) |
| - Satisfaction with the location where the medication is taken or picked up | 7.6 (SD 2.0) |

Note: The number of respondents from the total sample ranges from 213 to 222 across these items.

### 3.8.2 Crack cocaine agonist pharmacotherapy

Participants were asked to indicate whether they currently received medication from a doctor to replace their crack cocaine use and to provide details about the medication and their experiences. Nine participants (1.9% of HRCCU-only or 1.7% of the total sample) reported receiving medication to replace crack cocaine. Of these, two reported dextroamphetamine/ dexamphetamine, while the remaining seven reported other crack cocaine agonist medication or were unsure of the specific medication (see Table 18). Participants rated their experience with treatment on a 10-point scale (1=very bad, 10=very good). The lowest ratings were for the effectiveness of the medication in stopping cravings (mean=6.3) and the ability to function while on the medication (mean=6.2), while the highest rating was for satisfaction with the prescribing doctor (mean=7.3). Findings should be interpreted with caution due to the small sample size (n=9).

Table 18. Crack cocaine agonist pharmacotherapy

| | **n or mean (SD)** |
|---|---|
| Medication to replace crack cocaine | |
| - Dextroamphetamine/dexamphetamine | n=2 |
| - Mixed amphetamine salts | n=0 |
| - Bupropion | n=0 |
| - Modafinil | n-0 |
| - Topiramate | n=0 |
| - Other | n=3 |
| - I don't know | n=4 |
| Satisfaction with crack cocaine agonist pharmacotherapy | |
| - Effectiveness in stopping cravings | 6.3 (SD 3.0) |
| - Ability to function with the medication | 6.2 (SD 2.9) |
| - Satisfaction with doctor prescribing the medication | 7.3 (SD 2.7) |

### 3.8.3 Treatment for mental health problems

Participants were asked if they currently received treatment for mental health issues. Among the respondents (n=514), 16.0% reported being in treatment. These individuals rated their mental health treatment on a 10-point scale (1=very bad, 10=very good), with an average rating of 6.3 for satisfaction with treatment and an average rating of 6.5 for usefulness of treatment (see Table 19).

Table 19. Treatment for mental health problems

| Variables (respondents) | % or mean (SD) |
|---|---|
| In treatment for mental health problems (n=514) | |
| - Yes | 16.0% |
| - No | 84.0% |
| Satisfaction with mental health treatment | |
| - Satisfaction with treatment (n=81) | 6.3 (SD 2.7) |
| - Usefulness of treatment (n=80) | 6.5 (SD 2.8) |

## 3.9 Quality of life, recovery, and more

Finally, we surveyed participants on a diverse range of topics, including quality of life, recovery, drug use, internet access, online drugs markets, social integration, and discrimination. Quality of life and recovery levels are often underreported metrics in addiction care, yet they provide crucial insights into overall wellbeing. Internet access may open doors for e-Health interventions, offering new ways to support recovery. We also examined the use of online drug markets, given their increasing prevalence in other European countries. Additionally, social integration and experiences of discrimination play significant roles in either supporting or hindering individuals on their path to recovery.

### 3.9.1 Quality of life

Participants completed the adjusted MANSA-7 to assess their quality of life. Only those who completed all 7 items were included in the analysis (n=499). The mean overall score was 6.1 on a 10-point scale (1=very bad, 10=very good). Satisfaction was highest for mental health (7.0) and lowest for financial situation (5.0) (see Table 20). Scores were comparable across the HROU and HRCCU-only groups.

Table 20. Quality of life scores

| | **HROU** Mean (range) | **HRCCU-only** Mean (range) | **Total sample** Mean (range) |
|---|---|---|---|
| MANSA-7 mean score | 6.0 | 6.3 | 6.1 |
| - Satisfaction with quality of life as a whole | 6.0 (1-10) | 6.3 (1-10) | 6.1 (1-10) |
| - Satisfaction with living situation | 5.6 (1-10) | 6.0 (1-10) | 5.7 (1-10) |
| - Satisfaction with physical health | 6.6 (1-10) | 6.9 (1-10) | 6.7 (1-10) |
| - Satisfaction with mental health | 7.0 (1-10) | 7.0 (2-10) | 7.0 (1-10) |
| - Satisfaction with social relationships | 5.9 (1-10) | 6.3 (1-10) | 6.0 (1-10) |
| - Satisfaction with daily activities | 6.0 (1-10) | 6.3 (1-10) | 6.1 (1-10) |
| - Satisfaction with financial situation | 4.9 (1-10) | 5.4 (1-10) | 5.0 (1-10) |

Norm scores are available for MANSA-12 but not for MANSA-7. To facilitate comparison, scores were recalculated from the adjusted 10-point to the original 7-point scale, enabling approximate alignment with MANSA-12 norms. This provides a broader context for interpreting our findings. However, the recalculated scores are only an approximation and should be interpreted with caution due to differences in scales. A direct comparison can not be made.

The recalculated MANSA-7 mean score was 4.2 for HROU participants, 4.41 for HRCCU-only participants, and 4.27 for the total sample. In comparison, the total mean score for MANSA-12 was 5.74 for the Dutch general population (healthy adults), 4.19 for OAT patients receiving methadone, and 4.29 for patients with psychiatric

problems (Van Nieuwenhuizen et al., 2017). Thus, the findings are in line with previous mean scores for OAT patients and patients with psychiatric problems, demonstrating that these individuals have significantly lower quality of life compared to the general Dutch population.

### 3.9.2 Recovery

Participants completed the adjusted INSPIRE-O to evaluate their recovery (for details on the items, see the Methods section in Chapter 2). Only those who completed all 5 items were included in the analysis (n=488). The mean score for the total sample was 6.4 on a 10-point scale (1=very bad, 10=very good) (see Table 21). The mean score did not differ between the HROU and HRCCU-only groups.

Table 21. Recovery scores

| | HROU | HRCCU-only | Total sample |
|---|---|---|---|
| INSPIRE-O mean score | 6.3 | 6.6 | 6.4 |

To facilitate comparison with available norm scores for the INSPIRE-O, the scores were recalculated from the adjusted 10-point to the original 5-point scale. This enables approximate alignment with the INSPIRE-O norm score and provides a broader context for interpreting our findings. However, the recalculated scores are only an approximation and should be interpreted with caution due to differences in scales. A direct comparison can not be made.

The recalculated scores are totalled and multiplied by five, so the total score ranges from 0 (low recovery support) to 100 (high recovery support). The recalculated mean score was 79.6 for the total sample, 78.6 for HROU participants, and 83.0 for HRCCU-only participants. In comparison, the Danish general population norm for personal recovery has a mean score of 71.1 (Moeller et al., 2023), while a patient population norm of people with mental health issues (depression, anxiety, personality disorder) seeking treatment has a mean score of 39.9 (Moeller et al., 2024). The findings suggest that participants with HROU and HRCCU-only reported higher recovery support levels than the general population and clinical populations.

Fieldworkers observed that many participants gave themselves the highest scores, even when it was evident they were "clearly not doing well." This suggests that the findings may have been affected by social desirability bias or other unforeseen factors. As a result, the quantitative scores on recovery may not be entirely valid.

### 3.9.3 Other topics

Table 22 summarizes data on a range of different topics, including drug use, internet access, online drugs markets, social integration, and discrimination. Among respondents, 35.3% expressed a desire to stop using drugs and 28.7% wanted to reduce their drug use. Less than half (46.5%) reported having a smartphone with sufficient internet access. Nearly all participants (98.8%) purchased drugs offline rather than through online platforms. A substantial proportion reported feeling either a little (24.6%) or not at all (15.0%) integrated in society. Many experienced discrimination from service providers always (6.2%), often (13.8%), or sometimes (22.4%).

Table 22. Drug use, internet access, online drugs markets, social integration, and discrimination

| | Percentage of the total sample |
|---|---|
| Do you currently want to change your drug use? | |
| - No | 30.8% |
| - Reduce use | 28.7% |
| - Stop use | 35.3% |
| - Increase use | 5.3% |
| Do you have a smart phone with sufficient internet access? | |
| - Yes | 46.5% |
| - No | 53.5% |

| | |
|---|---|
| In the past 12 months, did you buy drugs online? Multiple answers possible. | |
| - No | 98.8% |
| - Yes, from the Dark Web/Dark Net | 0.2% |
| - Yes, from Web shops/ the normal Internet | 0.6% |
| - Yes, other (e.g. social media, forums) | 0.8% |
| Do you feel that you participate and are integrated in society? | |
| - Not at all | 15.0% |
| - A little | 24.6% |
| - Partially | 13.8% |
| - Mostly | 27.3% |
| - Completely | 19.3% |
| How often do you feel discriminated by service providers? | |
| - Never | 37.4% |
| - Almost never | 20.1% |
| - Sometimes | 22.4% |
| - Often | 13.8% |
| - Always | 6.2% |

Note: The number of respondents from the total sample ranges from 511 to 513 across these items.

## 3.10 In-depth analysis of people who were not born in the Netherlands

Additional analyses were performed to explore the extent to which people who were not born in the Netherlands or who do not speak Dutch may constitute a particularly vulnerable population.

Access to addiction care

Access to addiction care, as reflected by the 'in-LADIS rate', was higher among people born in the Netherlands (62%) compared to those born in EU or non-EU countries (46%). This disparity highlights potential challenges faced by non-Dutch-born individuals in accessing addiction care.

Among HROU, people not born in NL were less in addiction care (53.8%) than those born in the Netherlands (67.6%). Also among HRCCU-only, people not born in the Netherlands were less in addiction care (27.2%) than those born in the Netherlands (37.0%). The implications of this are even greater for the HRCCU-only group than the HROU group, as the HRCCU-only group consists of a greater proportion of non-Dutch individuals (63.8%).

Table 23. Differences in access to addiction care between people born in and outside of the Netherlands

| | **Total population** | | **HROU** | | **HRCCU-only** | |
|---|---|---|---|---|---|---|
| | Born in NL | Not born in NL | Born in NL | Not born in NL | Born in NL | Not born in NL |
| Proportion of the sample | 48.7% | 51.3% | 52.7% | 47.3% | 36.2% | 63.8% |
| In-LADIS rate | 62% | 46% | 67.6% (CI: 60.8% - 74.0%) | 53.8% (CI: 46.3% - 61.1%) | 37.0% (CI: 23.2% - 52.5%) | 27.2% (CI: 17.9% - 38.2%) |

Table 24 further highlights the disparity in access to addiction care between individuals born in the Netherlands and those not born in the Netherlands, particularly within the HRCCU-only group. Among HRCCU-only individuals in addiction care, 73% are Dutch. In contrast, among HRCCU-only individuals recruited in the field, only 36.2% are Dutch.

Table 24. Proportion of participants born in the Netherlands

| | **Registered in LADIS** | **OPAAK field sample** |
|---|---|---|
| HROU | 65.7% born in NL | 52.7% born in NL |
| HRCCU-only | 73.0% born in NL | 36.2% born in NL |

Access to opioid agonist treatment
Within the HROU group, people born in the Netherlands were more likely to be in OAT than those not born in the Netherlands (62% versus 38%, respectively).

Injection drug use
Among participants with past-year IDU, 59.6% were born in the Netherlands, while 40.4% were not born in the Netherlands. Comparative data from previous studies (in 2008 or 2012) is unavailable.

Language skills
To enhance inclusivity during recruitment, questionnaires were made available in both Dutch and English. The proportion of participants who completed the questionnaire in English was comparable across groups: 12% of HROU individuals and 9% of HRCCU-only individuals. Although 51.3% of participants were not born in the Netherlands, only 11% of the total sample completed the questionnaire in English, suggesting that many non-native individuals had learned the Dutch language.

Health care
The proportion of people with Dutch health insurance was higher among those in LADIS (93%) than those not in LADIS (73%). This means that most individuals accessing addiction care (93%) had Dutch health insurance; although it is also interesting to note that 7% accessed addiction care without Dutch health insurance. Among those not in addiction care, 73% had Dutch health insurance, suggesting they were eligible for care but did not utilize available services, indicating a considerable gap in service provision.

## 3.11 Conclusions

Descriptive characteristics reveal similarities as well as important differences between the HROU and HRCCU-only groups. They share many characteristics, suggesting that they are, in many regards, part of the same population. However, there are also notable differences. Compared to the HROU group, HRCCU-only individuals are younger, more likely to be born in a non-EU country (as opposed to the Netherlands), more likely to reside in homeless shelters/night shelters, less likely to stay in assisted living facilities, and less likely to use drug consumption rooms. They also engage less in addiction care; a pattern that was already observed in a 2008 PSE study. A possible explanation for this is the absence of an effective treatment comparable to OAT for crack cocaine. Implications of the similarities and differences in population characteristics are discussed in the General Discussion.

# Chapter 3. Assessment of Opioid Agonist Therapy and Needle and Syringe Program coverages

Analysis of data collected in the questionnaire for population size estimates

**Assessment of the coverage of Opioid Agonist Therapy and Needle and Syringe Programs**

# Opioid Agonist Therapy coverage

## Introduction and methods

Opioid agonist therapy (OAT) is an evidence-based approach to managing opioid dependence, utilizing medications such as methadone, buprenorphine, or pharmaceutical-grade heroin (diacetylmorphine). OAT coverage refers to the proportion of individuals with opioid dependence who have access to and receive treatment using medications like methadone. This is a key indicator of the availability and utilization of OAT within a given population.

OAT coverage is calculated by: "dividing the number of reported OAT clients by the estimated number of problem opioid users, using recent estimates of the number of opiate-dependent problem opioid users" (with 'recent' being defined as an estimate less than five years old) (EMCDDA & ECDC, 2014, p.11). In this study, OAT coverage is calculated using two methods:

Method 1: The number of OAT patients registered in LADIS divided by the total estimated number of people with HROU in the Netherlands.

**Formula: OAT patients in LADIS / PSE of people with HROU**

Method 2: The number of OAT patients in the fieldwork sample divided by the number of HROU in the fieldwork sample. This method provides a cross-validation estimate, as it should align closely with the results of the first method.

**Formula: OAT patients in fieldwork sample / people with HROU in the fieldwork sample**

## Findings

Method 1: OAT patients in LADIS / PSE of people with HROU

3,416 / 13,309 = 25.7%

Method 2: OAT patients in fieldwork sample / people with HROU in the field work sample

235 / 393 = 59.8%

## Discussion

Contrary to expectations, the two methods yield significantly different results for OAT coverage. The first method underestimates the true coverage, because it relies on data from LADIS. Not all addiction care institutes deliver data from OAT patients to LADIS, and a growing number of patients receive OAT from general practitioners, who do not all report to LADIS (J. Wisselink, personal communication, April 2024). Therefore, the second estimate is likely more accurate. However, also that estimate needs to interpreted with caution as the representativeness of the study sample may be limited. For example, OAT patients with stable lifestyles are less likely to be identified in the field, and may therefore yield a lower OAT coverage.

Our data suggests that **more than half of people with HROU (59.8%) had access to OAT in 2023**. While this does meet the WHO minimum target of 40% OAT coverage, it is lower than in other European countries, such as Germany, France, and Norway, where OAT coverage rates are at 80% or more (EUDA, 2024). Moreover, the OAT coverage appears to be lower than in 2012 when it was approximately 80% (Cruts et al. 2013). A comparison between these two studies needs to be made with caution as the representativeness of the two study samples is not necessarily comparable. Nevertheless, the lower OAT coverage is plausible, given age-related deaths of older OAT clients and an observed increase in migrants and undocumented people who struggle to access OAT (M. Busz, personal communication, December 2024).

# Needle and Syringe Program coverage

## Introduction and methods

Needle and syringe programs (NSP) are a public health intervention designed to provide sterile injecting equipment to people who inject drugs (PWID). These programs are crucial for preventing the spread of blood-borne infections like HIV and Hepatitis C among PWID. NSP coverage refers to the extent to which PWID can access and utilize sterile injecting equipment provided by these programs. Although the prevalence of injection drug use is low (about 12% among HROU individuals, see Chapter 2), good NSP coverage remains important to protect public health.

NSP coverage is often measured by the number of syringes distributed per person who injects drugs annually. Specifically, "NSP coverage is calculated by dividing the number of syringes given out in a given year by the estimated number of PWID" (with the estimate being less than five years old) (EMCDDA & ECDC, 2014, p.11). However, in the Netherlands, no data is available on the number of syringes distributed or the estimated number of PWID. Therefore we used an alternative method, which is endorsed by the European Union Drugs Agency (EUDA). The World Health Organization (WHO) Global Health Sector Strategy (GHSS) on viral hepatitis (which was adopted by 184 Member States at the World Health Assembly in May 2016) has service delivery targets relevant to HCV. The 2030 target is for each PWID to receive 300 syringes per year (International AIDS Society, 2018).

According to the WHO, NSP coverage is calculated as the mean number of clean syringes per PWID per year divided by the WHO target of 300 clean syringes per person who injects drugs per year.

**Formula: Mean number of clean syringes per PWID per year / 300 clean syringes per PWID per year**

However, also the WHO target has limitations, as it does not take into account injection frequency. As injection frequency can vary, this may lead to faulty or skewed results. We therefore applied an adjusted methodology in which we calculated the NSP coverage on a case-by-case basis. For example, an individual who injects once a week (52 times a year) and obtains 52 clean syringes has a 100% coverage. For comparison, according to the WHO target of 300 syringes per year, the coverage would only be 17% (52/300).

In order to calculate the NSP coverage using our adjusted methodology, we collected the following data from people who use drugs using a brief questionnaire:

- whether they injected any psychoactive substance(s) not according to medical prescription in the last 12 months (case definition IDU) (EMCDDA, 2013)
- number of clean syringes acquired per day/ week/ month/ year
- injecting frequency per day/ week/ month/ year

Values were recalculated to a common denominator ('per week'). The NSP coverage was determined using the following approach:

**Adjusted formula: Number of clean syringes obtained / Injection frequency**

Example data:

| Ps | Injection frequency | Frequency of getting needles | Number of needles | Frequency of getting needles x number of needles = Total needles | **Total needles/ injection frequency = coverage** |
|---|---|---|---|---|---|
| 1 | 5x week | 1x week | 10 | 1x 10 = 10 needles per week | 10/5 = **200%** |
| 2 | 2x day | 1x day | 3 | 1x 3 = 3 needles per day | 3/2 = **150%** |
| 3 | 4x day | 1x day | 5 | 1x 5 = 5 needles per day | 5/4 = **125%** |

## Findings

Of the 47 participants who reported past-year IDU, 28 provided sufficient data to estimate the NSP coverage. While the prevalence of IDU is relatively low in the Netherlands (12% among HROU participants), there is no current estimate of the number of PWID, making it difficult to assess whether the sample size is large enough. However, these 28 individuals were part of a representative sample of people with HROU and HRCCU-only. Therefore, this data provides the best available real-world indication of NSP coverage in the Netherlands to date.

Injection frequencies varied widely, ranging from once a year to several times a month or week (57% of participants). Less than half (12 of the 28 participants) injected daily. Given these variations, we used our adjusted methodology to calculate the NSP coverage on a case-by-case basis.

Of the 28 individuals, 25 had an NSP coverage of 100% or more (range: 100% – 2,000%), while 3 had a coverage of less than 100% (range: 48% – 86%). The median NSP coverage was 169%, meaning **participants typically had approximately 1.7 clean syringes available per injection**. The middle 50% of participants had coverage between 100% (Q1) and 525% (Q3).

## Discussion

The median NSP coverage in our sample was 169%, meaning participants typically had more than one clean needle available for every time they injected. This indicates that PWID generally have sufficient access to clean syringes, eliminating the need to reuse or share them. The WHO recommends that PWID have access to 300 clean syringes per person per year. If this target assumes daily IDU, with 365 days in a year, 300 clean syringes equates to a minimum coverage of 82%. The NSP coverage in the Netherlands exceeds this minimum target proposed by the WHO.

New groups of PWID, such as those engaging in chemsex, were not included in this study, as this would have required a different recruitment strategy. These individuals often obtain injecting equipment from sources like the internet rather than harm reduction services. NSP coverages should account for all PWID - independent of the context of use - as it is intended to measure the overall availability of clean injecting paraphernalia within the entire PWID population. Therefore, it is important to acknowledge that the NSP coverage in this study refers to the more ‘traditional’ group of PWID. Future research should also evaluate syringe availability and safe injection practices in other groups of PWID, such as those engaging in chemsex.

# Chapter 4. Needs assessment of people with high-risk opioid use (HROU) and people with high-risk crack cocaine use without high-risk opioid use (HRCCU-only)

Analysis of focus groups and individual interviews

**Needs assessment of people with high-risk use of opioids and crack cocaine**

# Introduction

Individuals with high-risk use of opioids and crack cocaine face complex challenges, including significant physical and mental health burden. The population is aging, and their needs are evolving. Additionally, many experience reduced quality of life due to social isolation, discrimination, and dissatisfaction with their personal development and sense of purpose. Addressing these issues with adequate support is essential to improving their wellbeing and preventing further deterioration.

This study represents a needs assessment of people with high-risk use of opioids and crack cocaine in the Netherlands. The aim was to identify the care and support needs of this population. Using an exploratory qualitative research approach, we sought to understand their experiences and needs, focusing particularly on uncovering unmet needs from the participants' perspectives.

# Methodology

## Data collection

**Recruitment**
Participants were recruited using two approaches. First, we recruited individuals using contact information that was obtained from a prior questionnaire administered as part of the OPAAK study (see Chapter 3). This questionnaire included an option for participants to provide their details to be contacted for further research. Additionally, participants were recruited directly at low-threshold harm reduction services and assisted living facilities. These facilities not only allowed the researchers on-site visits to conduct interviews, but also assisted in identifying potential participants. To maximize inclusivity, a combination of pre-arranged appointments and on-the-spot recruitment was employed. The latter was valuable for engaging individuals who might struggle with maintaining scheduled commitments.

Inclusion criteria were the same as for the main study (see Chapter 3). Individuals needed to be aged 18 or older, self-report high-risk use of opioids and/or crack cocaine (as defined by the EUDA criteria), and reside in the Netherlands for at least three months. We aimed to recruit 40 participants, in line with qualitative research guidelines. Participants were recruited in five geographically diverse cities: Amsterdam, Rotterdam, Utrecht, Haarlem, and Heerlen.

**Focus Groups and interviews**
Data collection was conducted through focus groups and individual interviews, each lasting approximately one hour. Sessions were held in a quiet room at selected facilities. Focus groups were facilitated by two researchers, while individual interviews were conducted by one researcher. A topic guide was used (see Appendix B). The topic guide addressed participants' experiences with care and support services, their service needs, and what they would change about available services. Participants received 20 Euro in cash upon completing a focus group or interview.

All sessions were audio-recorded and transcribed. Transcriptions were pseudonymized by replacing participant names with unique identifiers, so that information could not be traced back to individual participants.

## Analysis

Thematic analysis was employed to identify both explicit and implicit needs and preferences expressed by participants. This flexible and nuanced approach allowed for the identification of needs that participants may not have been able to articulate directly, but which become evident through analysis of their experiences.

# Results

The findings address three main questions: (1) How do participants perceive available care and support services?, (2) What changes would participants make to existing care and support services?, and (3) What would participants add to existing services? Answers to the first two questions were informed by participants' experiences with care and support services, either personally or via others. Here we focused on their experiences, what is going well, and what can be improved. Finally, we explored unmet needs for which there are no existing services yet.

## Participant overview

The sample included 27 individuals with high-risk opioid use (of which some also used crack cocaine) and 13 individuals who only used crack cocaine and no opioids. While no quantitative sociodemographic data was collected, field notes provided the following insights about the participants:

The **age range** of participants was varied, including younger participants aged between 20 and 25 years as well as older participants aged 70 years and above. The most represented age group was between 50 and 70 years.

Participants' **ethnic backgrounds** were diverse, encompassing both individuals with and without migration backgrounds. Some participants mentioned that they were from Suriname, the Dutch Antilles, Morocco, Turkey, and Poland.

Participants were **residing** in urban areas in the five cities of recruitment. Several participants stayed in temporary shelters, such as 24-hour-shelters and night-shelters. Most participants lived in assisted or protected living facilities, and a few lived in their own housing without support.

**Other characteristics** include health issues that were reported by many participants. These were often self-attributed to the long-term use of significant amounts of alcohol and drugs. Participants experienced problems related to their cardiovascular and respiratory systems as well as physical mobility. Other complaints included difficulty sleeping and loneliness. Some participants were undergoing treatment or had undergone surgeries for their conditions.

## Experiences and needs within existing care and support services

The current care and support services meet many of participants' needs. Participants generally reported both positive and negative experiences with existing services. In this section, we describe participants' experiences with various care and support services and how they do and do not meet the needs of clients.

**Knowledge of services is limited to personal experiences**
Several participants indicated that there is sufficient availability of services in their area and that when they experience a problem, they know where to seek help, and this help is provided. However, this did not apply to all locations where the study was conducted. In some cities, participants primarily mentioned a lack of services. Participants seemed to be mostly aware of services they had personally used. For example, participants who only used crack cocaine were less aware of where to access methadone treatment. Similarly, participants who could use drugs in their own homes were less aware of where drug consumption rooms are located. Thus, participants' knowledge of available services was primarily based on personal experience or contact with other individuals (i.e., via word of mouth). Individuals who were relatively new to the scene often had limited knowledge of available services.

**Positive or negative experiences with care depend on the individual**
All participants had multiple and varied experiences with care and support services, making it difficult to provide a generalized overview. Many participants reported receiving good assistance when they needed care or support. At the same time, nearly all participants also had negative experiences. For example, some felt that they were not taken seriously or that medical assistance was only provided when their medical condition was severe. According to participants, this often depended on the individual care provider and their attitudes

toward people who use drugs. Some care providers were described as highly distrustful of patients. One participant described that, when they requested an increase in their methadone dosage, the doctor assumed they intended to sell it. At the same time, participants also described care and support providers who were understanding and supportive, because they had a non-judgmental attitude.

**Need for more respectful treatment**
Issues around the attitude of care providers were also reflected in how participants were treated. Participants expressed frustration when professionals adopt a condescending manner, describing it as belittling:

> *"(..) then you're treated like little children."* (Participant, Amsterdam)

Participants noted that care providers sometimes failed to distinguish between more experienced users and individuals who are relatively young and new to the drug scene. These participants called for different approaches for the two groups, as experienced users often know what their needs are and they want to be treated more equally. Some professionals reportedly acted in an authoritarian manner towards clients. For instance, one participant was denied methadone because she arrived late to an appointment. The participant explained:

> *"They don't understand what your life is like, and they don't take the time."* (Participant, Utrecht)

**Privacy not always respected**
Some participants complained about having to share more and more irrelevant information to be able to access care and support. Examples included having to fill in lengthy forms with excessive questions, and care providers attempting to contact participants' children. This is perceived as a breach of privacy. Participants noted that this can create barriers for some individuals, discouraging them from seeking or continuing to seek help.

**Lack of sufficient spaces and long waiting lists**
While most participants had positive experiences with access to services, several individuals observed that access had worsened in recent years. They attributed this to the closure of facilities, which has led to a reduction in available spaces for shelter and treatment. As a consequence of this, there are long waiting lists:

> *"By the time it's your turn, it takes so long. For detox, it's almost two months. They don't have room. In the meantime, you're spending a fortune to keep buying on the street."* (Participant, Amsterdam)

The waiting lists make it so that someone who needs help gets into even more trouble before they finally receive help. In some cases, the delays lead to people avoiding care altogether, feeling that they would not be helped anyway.

**Call for preventive check-ups and care**
A few participants called for more regular medical check-ups from a preventive perspective. They compared this to routine cancer screenings or preventive breast cancer exams for women. Given the higher health risks associated with substance use, participants felt such preventive measures would be beneficial. Other participants reported already receiving regular check-ups from their general practitioner or other medical services and appreciated that this was being done.

**Inconsistent treatment across changing care providers**
Participants frequently mentioned issues stemming from changes in care providers, such as changes in their treatment. Inconsistencies in treatment can have both positive and negative consequences:

> *"I was always prescribed benzos by my old doctor. The new one didn't think that was a good idea."* (Participant, Amsterdam)

A reluctance to prescribe medication was often cited as a negative experience. While participants understood that doctors want to prevent misuse or illicit trade of medications, they felt that the mistrust of some physicians goes too far. Participants largely attributed this to stigmatization for their drug use.

**Social contact and daytime activities not to be underestimated**
Nearly all participants used social services in the cities where they resided, such as facilities offering daytime activities ('dagbesteding') or social support. Participants were generally positive about these services, often noting that they were treated better in these settings than in healthcare environments:

> *"Yeah, they're good here. They just treat you normally here."* (Participant, Heerlen)

Facilities offering work opportunities for a small compensation were highly appreciated, as they helped participants cover minor expenses like tobacco or beer. Several participants also emphasized the social benefits of such places, as they often felt lonely and are unwelcome elsewhere. For instance, an older participant (aged 70+) in Rotterdam attended a daytime activity centre ('dagbesteding') on a daily basis to fold garbage bags into packs of two for other clients who cleaned the streets. While seemingly mundane, this task held great value for him:

> *"Like I said, I've been sitting alone at home for twenty years. (…) It's good like this, a bit of relaxation. Yeah, having coffee and doing those bags… Yeah, it's something to do. Nice people, good atmosphere."* (Participant, Rotterdam)

**Methadone and heroin distribution: sufficient and effective, but not for everyone**
All participants who used opioids had experience with methadone distribution, and most reported positive experiences:

> *"If you have methadone, you don't have to steal, rob, or deal, but you do need to be on an adequate dose."* (Participant, Utrecht)

Participants used methadone to avoid withdrawal symptoms when they did not have heroin or, in some cases, as a step toward quitting heroin use. However, some participants criticized the restrictive rules limiting access to methadone. Some felt that they were consulted insufficiently when determining their dosage or schedule for when to pick up their medication. Moreover, the method of methadone distribution varied by city. In some locations, participants had to pick it up from a doctor or health service ('GGD'), while in others, it was delivered to their homes by a pharmacy.

One participant who received medical-grade heroin through a public health service ('GGD') was satisfied with this arrangement. However, other participants who used opioids felt that heroin-assisted treatment was not suitable for them due to the high purity (and potency) of medical-grade heroin or the extensive conditions attached to accessing it.

## Unmet needs

In addition to discussing their experiences with existing services, participants also spoke about what they felt was missing. This included non-existing facilities, treatment options, a lack of services for specific target groups, as well as certain skills among care and support professionals.

**Outreach care**
While many participants were able to express their needs and ask for help when required, there were others who struggled to do so or simply did not try. For example, when asked about additional needs beyond daytime activities and medical care, one participant expressed a desire for new clothing. Although he knew he could obtain it through a facility, he hesitated to ask for it. Such conversations with participants often revealed that they do not always fully understand how the care system works, which can lead to a 'why bother' attitude. This is a target group that is easily overlooked, especially when they are not outspoken or do not articulate their needs clearly. These findings highlight the need for more proactive and outreach-focused care.

**Care without pressure towards abstinence**
Much of the care described by participants was focused on changing their drug use. Many had undergone detox programs, substitution treatments, or other addiction interventions to stop or reduce their substance use. These services were well-known among participants and some planned to continue using them.

However, some older participants mentioned that they no longer wanted such interventions. They had come to terms with their situation and wanted support, but not support aimed at changing their substance use:

> *"After 40 years of using, my body won't appreciate quitting (…) I might have ten years left, and that'll be it. I'm lucky to have made it this far."* (Participant, Rotterdam)

Participants did not share what this kind of support would look like. However, one participant was positive about a facility where her partner lived, where his substance use was accepted as it was:

> *"[Facility name, redacted] is the 'final stop.' He's doing well there because they just accept it."* (Participant, Amsterdam)

**More spaces to use substances**
A recurring wish among participants was for more places where they could use substances without being disturbed. Some participants went to drug consumption rooms, but noted that they did not want to spend the whole day there, nor were they always permitted to do so. Some participants stayed in living facilities where they were not allowed to use substances in their rooms. Similarly, at locations offering daytime activities ('dagbesteding') or work, there were often no designated areas for substance use, leading participants to use secretly in the bathroom:

> *"It's not allowed, but if I do it on the street, the police will take me."* (Participant, Heerlen)

**Quality and work methods of staff at care and support services**
Participants voiced critical opinions about the quality and work methods of staff at care and support services. Many expressed frustration about the limited expertise and experience of care professionals:

> *"They never have proper training; they're all interns."* (Participant, Utrecht)

Several respondents noted that staff at care and support services often lack practical knowledge: they can't answer questions, lack practical experience, and often have insufficient knowledge about drugs.

The criticism was not only about knowledge, but also the lack of a personalized approach to care. Participants advocated for more person-centred support:

> *"You need someone to sit next to you, stay with you, keep you engaged."* (Participant, Amsterdam)

They emphasized the need for personalized support, for example like a buddy-like program where attention to the individual is central. Many participants stressed that care should go beyond protocols and methods. They did not want to feel like a 'number'. They wanted staff at care and support services to truly stand by them, do what is necessary, provide more attention, and take the time to get to know them. One suggestion was to involve more people with lived experience and peer supporters to achieve this.

**Access to care for new target groups**
While all participants had legal residency in the Netherlands, they expressed concerns about the care gap for individuals without residency status, such as labour migrants and asylum seekers. They observed that these groups faced significant barriers to accessing adequate care and support. They also suggested that these groups might have other care needs compared to more established populations, stemming from differences in how they use substances and their knowledge about drugs and the healthcare system.

## Care and support for people using crack cocaine

There are various indications that crack cocaine (also known as basecoke) plays an increasingly significant role in the drug scene. We therefore asked participants specifically about their experiences and needs regarding the use of crack cocaine. Unlike for opioids, there is no effective agonist medication and only few tailored harm reduction services for crack cocaine.

**Perceptions of available care and support services**
Participants generally felt that there were limited harm reduction and support services specifically for crack cocaine users. While addiction care is available for all substances, one participant noted that such care often does not align well with the unique dynamics of crack cocaine use. Treatment options were described as overly focused on detoxification, insufficiently intensive, and too brief. This disconnect may be because the care system is modelled on the treatment of heroin addiction, which is characterized by pronounced physical withdrawal symptoms. In contrast, crack cocaine withdrawal is driven more by psychological cravings rather than physical dependence:

> *"It lingers in your mind."* (Participant, Amsterdam)

This participant explained that crack cocaine use requires a fundamentally different type of support.

Another participant highlighted the irregularity of crack cocaine us compared to opioids:

> *"Heroin is needed every day, but basecoke is not."* (Participant, Heerlen)

As a result, some participants did not perceive their crack cocaine use as problematic or addictive, but rather as something they engaged in simply because they enjoyed it.

**Medical crack cocaine prescription and substitution treatment**
Participants discussed the potential of treatment and harm reduction interventions for crack cocaine, which are similar to opioid substitution treatment and heroin distribution for people using opioids. Opinions on medically prescribed crack cocaine were diverse. Participants identified potential advantages and disadvantages, extending beyond just medical considerations.

One argument centred on financial relief. Participants suggested that prescribing crack cocaine could reduce the financial burden on those who use it, leaving more money for basic necessities. Participants also linked this to criminal activities, pointing out that the daily need to obtain money is a major reason that people who use drugs frequently encounter the justice system. Prescribing crack cocaine could alleviate this financial pressure and help reduce crime and periods of incarceration among those who use it.

However, some participants were critical of the idea of crack cocaine prescription, arguing that crack cocaine is fundamentally different from other addictive substances. Some raised concerns that it might encourage more extreme or uncontrolled use:

> *"There's no limit; people will start doing crazy things."* (Participant, Heerlen)

Others suggested that prescription of crack cocaine might lead to boredom: *"It would get boring."* (Participant, Rotterdam) This sentiment seemed to point to a deeper underlying need, such as a sense of purpose or meaning in life, which was currently being filled or masked with substance use.

Effective substitution treatment for crack cocaine appeared to be a complex issue and no clear solutions were offered. Some participants mentioned that they received medications that helped ease withdrawal symptoms:

> *"I get medications that make it hit less tough if I don't use basecoke."* (Participant, Rotterdam)

However, others saw little benefit in substitution methods. One participant firmly stated that no suitable substitution exists for crack cocaine, arguing that currently available alternatives (such as dexamphetamine) are even more harmful than crack cocaine itself. Participants emphasized that effective treatment is further complicated by underlying social conditions. They said that achieving stability is challenging for those who are homeless, living on the streets, unemployed, lacking support groups, or without a supportive social network.

## Discussion and recommendations

This needs assessment explored the experiences and needs of people with high-risk use of opioids and/or crack cocaine in the Netherlands. We interviewed a diverse group of participants about their experiences with existing care services and identified gaps in the care provided. While participants were generally positive about available services, they also pointed out critical issues, including stigma, a lack of personalized care, insufficient outreach services, and deficits in specialized care, particularly for people using crack cocaine. Although exploratory, these findings highlight potential systemic challenges in current care provision and suggest areas for improvement.

**Reducing stigma and social isolation**
Stigma emerged as a significant barrier to effective care. Participants felt that they were often perceived as less deserving of care due to their status as 'drug users', which negatively impacted their self-esteem, help-seeking behaviour, and overall care experiences. In some cases, stigma coincided with social isolation and loneliness. To address these issues and reduce experienced stigma, promoting low-threshold social interventions is essential. Initiatives that involve people with lived experience and peer supporters can foster a sense of community, improve social connections and a sense of purpose. Creating safe spaces where individuals can engage in social activities or connect with others could further enhance social inclusion. Although such interventions already exist in the Netherlands to some extent, their scope and accessibility should be further expanded to maximize their impact.

**Enhancing outreach strategies**
For individuals with low health literacy or a less proactive approach to engaging with care services, outreach strategies are critical. In the past, initiatives existed where field workers visited drug scenes and users, engaging them in conversations about care options and providing on-the-spot assistance. This included mobile service vans which made it easier to provide comprehensive and adequate support. Revitalizing and expanding such initiatives could improve service awareness and uptake among new or disengaged individuals. While the Mainline Foundation currently conducts some outreach work, additional resources are needed to sustain and scale up these efforts and carry out the work effectively.

**Specialized care for specific subgroups**
Participants emphasized the lack of specialized care services, particularly for subgroups, including older individuals, people without legal residency, and those using crack cocaine. Current care and services often fail to address the unique challenges faced by these groups. Particular attention should be directed towards developing specialized care pathways that prioritize people who use crack cocaine and non-abstinence-based care (e.g. for those in palliative care or those unwilling to pursue abstinence). Additionally, more attention should be paid to social and psychosocial support. This aligns with the broader call in addiction care for a more holistic approach to treatment, which addresses not only substance use but also underlying social and psychological needs, such as housing, employment, and rebuilding social relationships.

**Improving care provider attitudes and approaches**
The attitudes and approaches of care providers warrant attention, as they significantly influenced participants' experiences in care. There are signals that care providers struggle with systemic pressures, such as long waiting lists and limited resources. This can constrain the providers' ability to offer personalized care. Participants often described interactions in care as impersonal, business-like, and lacking empathy. Several initiatives are underway to address these issues, which also affect other sectors of healthcare. These efforts include better integration of addiction care, mental health services, social work, and primary care networks. In addition, further training and sensitization of staff to people who use opioids and crack cocaine may be needed.

## Conclusion

This needs assessment highlights several areas of improvement in addiction care and support services for people with high-risk use of opioid and crack cocaine. Crucial steps toward improving outcomes for these vulnerable populations include expanding outreach strategies, developing specialized care pathways, addressing the stigma, and supporting care providers in delivering personalized care. These recommendations provide a foundation for future research and policy development aimed at creating more effective and person-centred addiction care.

# Chapter 5. New trends and groups of people with high-risk drug use

Analysis of focus groups and individual interviews with professionals

**New trends and groups of people with high-risk drug use**

# Background and objectives

The aim of this explorative study is to identify emerging trends and groups of people with high-risk drug use in the Netherlands. High-risk drug use refers to repeated drug consumption that either causes actual harm or places the individual at significant risk of harm. While existing monitoring systems can track changes in drug use within the general population, smaller or newly emerging groups of users are not captured well by these systems. Early identification of new groups with high-risk drug use and possible drug-related threats is critical for anticipating and mitigating risks and protecting public health.

**Definitions**
We adopted the definition of high-risk drug use from the European Union Drugs Agency (EUDA):

- **High-risk drug use** is defined as "recurrent drug use that is causing actual harms (negative consequences) to the person (including dependence, but also other health, psychological, or social problems) or is placing the person at a high probability/ risk of suffering such harms" (EMCDDA, 2013).

For the purposes of this study, we defined a new or emerging group of high-risk drug users as a distinct population that meets the following criteria:

- Engages in high-risk use of illegal drugs, including illegal or diverted medications or New Psychoactive Substances (NPS, also known as 'designer drugs' or 'research chemicals');
- Emerged or became significantly larger in the Netherlands in the past five years; and
- Is not well-represented in existing drug monitors, such as the National Health Survey ('Gezondheidsenquête') or the Drugs Information and Monitoring System (DIMS).

# Methodology

## Data collection

Data for this report was gathered from:

- A focus group with professionals from Amsterdam working in advocacy, research, fieldwork, treatment, and prevention.
- A focus group with Mainline fieldworkers who conducted the interviews for the OPAAK-study during one year and maintained contact with drug users across the country as part of their day-to-day work.
- Twelve individual interviews with members of Mainline's national peer network. This is a group of active users with access to various drug scenes in large and small cities with which Mainline fieldworkers maintain contact on a regular basis.
- Internal reports about the fieldwork conducted by Mainline in the past two years.

Focus group lasted about one hour and individual interviews lasted about 30 minutes. Participants were not compensated for their time.

The focus groups and individual interviews explored three core questions (see Appendix C):

- Which groups of high-risk drug users have emerged or grown significantly in the Netherlands over the past five years?
- How do these new user groups differ from existing groups?
- What research priorities should be recommended for the near future regarding the new user groups?

## Analysis

Focus groups and individual interviews were audio-recorded and notes were taken during and after each session. One researcher conducted all focus groups and interviews and listened to the recordings multiple times. Data was analysed using content analysis to identify patterns across transcripts. Particular attention was

paid to user characteristics, drug use patterns, and challenges in service provision, such as limited access to care for certain groups. Findings were discussed and refined in collaboration with colleagues to ensure validity.

## Results

The study identified nine groups of high-risk drug users that are new or emerging in the Netherlands and warrant further research. It is important to note that these findings are based on qualitative insights from experts in the field and subjective observations rather than quantitative data.

### 1. People using non-prescribed psychopharmaceuticals

The group of people using non-prescribed psychopharmaceuticals appears to have grown in recent years. These individuals use benzodiazepines, synthetic opioids, and other tranquilizers, often obtained from dealers or online shops of 'research chemicals'. The substances are typically sold as individual items in small, unlabelled packaging without clear identification or usage instructions, increasing the risk of misuse. The size and characteristics of this group remains poorly understood, but it seems to encompass a broad cross-section of society.

Especially the use of non-prescribed benzodiazepines and synthetic opioids raises critical concerns, including the risk of overdose, adverse side effects, and the development of dependence. For this group of users, as well as users of synthetic opioids obtained through legal prescriptions, there is reportedly a lack of support when individuals develop an addiction or want to taper off use. Withdrawal from these substances can often be severe and, in some cases, dangerous. Focus group participants highlighted that non-prescribed psychopharmaceuticals are often implicated in fatal or near-fatal overdoses. That is because these individuals are using substances that are not controlled or regulated, like in the healthcare system, and therefore potentially unsafe. Purchasing substances outside regulated sources, and the lack of insight into the exact content of these substances, poses serious health risks. Non-prescribed psychopharmaceuticals are usually not tested at drug checking services because they are classified as pharmaceutical products and therefore fall outside the scope of drug checking protocols.

### 2. Chemsex users within and beyond the traditional MSM group

Chemsex – the use of psychoactive substances to enhance sexual experiences – has traditionally been associated with men who have sex with men (MSM). Within the MSM chemsex scene, there has been a notable rise in the use of 3-MMC in recent years, which has largely replaced methamphetamine use among people who inject drugs. These individuals often experience severe complications from injecting 3-MMC. Due to the high frequency of injections, improper injection techniques, and potentially non-sterile injection materials, individuals often report severe abscesses and vascular problems.

Beyond the MSM chemsex scene, substance use in sexual contexts seems to be increasing in other groups, including swingers, students, transgender individuals, and sex workers. Many of these individuals have prior experience with substance use and bring this into a sexual context, while others have no prior drug use experience and encounter drugs for the first time in a sexual setting. This can lead to risky use due to a lack of knowledge or experience with substances. Moreover, first-time exposure to drugs in sexual contexts can create an association between the two, which can make it more difficult to reduce or stop substance use and increase the risk of problematic use and dependence. Drug use in sexual contexts often remains undetected by drug monitoring systems and addiction services, as standard intake procedures do not typically inquire about the context of drug use or its relationship to sexual behaviour.

### 3. Eastern European and undocumented homeless individuals

A significant number of Eastern Europeans who are living on the streets in the Netherlands are uninsured, lack access to healthcare, and use substances such as heroin, alcohol, crack cocaine, and speed. Many initially came to the Netherlands as work migrants. However, when they lose their jobs, often with exploitative and poor working conditions, they tend to also lose their housing. While some have prior substance use experience, others become exposed to drugs for the first time in the Netherlands. This often occurs in work settings to endure heavy labour, but also on the streets where substances are used as a way to cope with harsh conditions. This group generally faces limited access to methadone treatment and other forms of care due to

legal and bureaucratic obstacles, language barriers, and lack of insurance. Despite their entitlement to basic European healthcare, they generally struggle to navigate the system and access needed services.

Additionally, a growing number of undocumented homeless individuals are seen at low-threshold shelters. This group primarily includes individuals who became undocumented and fell into illegality after a failed asylum application or who never initiated an asylum procedure. Crack cocaine use is highly prevalent within this group. These individuals tend to have even less access to care than Eastern European individuals, leaving them particularly vulnerable to health issues.

### 4. Unaccompanied (formerly) underaged asylum seekers using non-prescribed medications

A particular group of concern are unaccompanied (formerly) underaged asylum seekers who use non-prescribed psychopharmaceuticals. A portion of this group – particularly those with low prospects of obtaining a residence permit or underlying psychological issues – uses medications such as Rivotril (an anti-epileptic medication, clonazepam) and Lyrica (an anti-epileptic medication, pregabalin) at disproportionately high rates. There are indications that these medications are relatively easily prescribed during the asylum process, without adequate support to address underlying issues. Reports from fieldworkers and police indicate that these unaccompanied (formerly) underaged asylum seekers develop a dependence on these substances and display erratic and misunderstood behaviour.

### 5. Expats with problematic drug use

Expats are individuals who typically reside in the Netherlands temporarily for work or study and are associated with certain privileges. A growing number of expats have been identified with rapidly escalating drug problems, both in treatment settings and within the chemsex scene. Experts reported that recreational drug use among expats often progressed quickly into problematic use. Contributing factors include difficulties with cultural adjustment, loneliness, easy access to drugs, limited prior drug use experience, lack of a supportive network, and poor access to prevention and treatment services. There is also limited availability of care in languages other than Dutch, especially for inpatient treatment. Cultural stigma around drug use, shame, and unfamiliarity with the Dutch healthcare system often delay help-seeking until problems become severe. These challenges highlight the need for tailored interventions to support this under-researched group.

### 6. People using New Psychoactive Substances such as 3-MMC

Despite the ban, 3-MMC and its variants remain highly popular. These substances are readily available across the Netherlands and are used by diverse societal groups in various settings. Much of this use occurs in private home settings, which allows usage to remain hidden until it escalates to problematic levels, prompting users to seek addiction treatment. While 3-MMC and its variants are commonly snorted, injection is prevalent within the chemsex scene. The rise in 3-MMC use appears closely linked to the COVID-19 pandemic, during which it gained popularity at small home parties. Young adults, in particular, experimented extensively with new substances, driven in part by the easy access of research chemicals through online platforms. These substances were often perceived as less risky compared to the traditional illicit drugs, contributing to their rapid rise in popularity. However, this dynamic complicates early identification of problematic use, leading to greater long-term risks for the health and well-being of this cohort.

In some regions, such as the west of Brabant and parts of Zeeland, alpha-cathinones like Alpha-PVP/PHP (also known as Flakka) have seen a rise in use in recent years. This trend is primarily observed among highly marginalized groups and is in many cases associated with rapid health deterioration, extreme behaviour, and an increase in mental health issues, particularly psychosis.

### 7. Young people in youth care and on the streets

Youth shelters frequently report high levels of cannabis use among their residents. Upon turning 18, these young individuals age out of the youth shelter system and lose access to structured support, leaving some homeless. The shortage of affordable housing further contributes to rising homelessness among young adults. Young individuals are often exposed to illegal substances on the streets or in youth shelters, and for some, this exposure transitions to the use of harder drugs than cannabis. Mainline fieldworkers increasingly encounter young people on the streets or in youth care who use substances like crack cocaine, speed, and 3-MMC. This group is particularly vulnerable due to their inexperience with drugs and precarious social circumstances,

which place them at greater risk of exploitation and harm within environments often dominated by older and more seasoned drug users.

### 8. People with mental health challenges experimenting with psychedelics

With the growing attention on the therapeutic potential of psychedelics such as ketamine and MDMA, experts have observed an increase in individuals self-medicating with these substances. Reports from drug testing services indicate that many individuals wish to test psychedelics with the intention of using it to alleviate mental health conditions, such as depression or trauma. However, current monitoring systems in the Netherlands have a blind spot for psychedelics. There are only very limited opportunities for testing psychedelics in the Netherlands, leaving most user groups unmonitored and out of sight.

While most users do not experience significant issues after using psychedelics, there are concerns about more vulnerable groups of individuals who seek to alleviate mental health problems through psychedelics. This may include people who have become disillusioned with traditional mental health care (e.g. the GGZ) or individuals who lack an official diagnosis for their symptoms. Self-medication with psychedelics can worsen existing mental health symptoms. Additionally, individuals with unresolved or suppressed trauma may experience a resurfacing of psychological issues after psychedelic use. For these individuals, access to specialized therapists is crucial to help them integrate their experiences and alleviate symptoms. Unfortunately, specialized psychedelic therapy and related therapeutic support is expected to remain largely unavailable in the Netherlands and across much of Europe for the foreseeable future.

### 9. People in detention

Another group that remains partially hidden consists of individuals in detention or other closed settings. Data on drug use in detention is limited, with only isolated studies shedding light on the issue. For example, a recent report from the Trimbos Institute documented the use of synthetic cannabinoids in detention settings. However, broader trends in substance use among incarcerated populations remain poorly understood.

Moreover, although some addiction and harm reduction services are available in detention, significant disparities exist between prisons, leading to uneven provision of care. This represents a missed opportunity, as detention provides a relatively stable environment in which individuals could undertake treatments, such as for Hepatitis C or substance dependence. Fieldworkers also reported that, after release from detention, many individuals face significant barriers when attempting to reconnect with harm reduction and healthcare services. There is little to no ‘transition management’, where formerly incarcerated individuals are actively and smoothly referred from in-detention care to community-based care upon release. This gap in continuity of care creates unnecessary risks, such as overdoses and treatment interruptions, particularly for individuals relying on opioid agonist therapy or other critical medical interventions. Addressing this issue could significantly improve post-detention outcomes.

## Conclusion

In recent years, new trends and groups of people engaging in high-risk drug use have emerged. Some groups have undergone rapid developments, while other trends have been ongoing for a longer period of time. Many of these groups are underrepresented in existing drug monitoring systems, because they belong to marginalized populations, such as undocumented migrants, people experiencing homelessness, and chemsex users. Moreover, certain forms of drug use occurs in hidden contexts, such as the use of NPS and self-medication with psychedelics in home settings. This makes it difficult to detect new drug-related risks and harms. As a result, emerging drug-related risks and harms often go unrecognized until they become severe. It is therefore crucial to identify new groups of drug users and provide tailored support and interventions at an early stage, before the groups grow in size or the harms intensify. While this research has identified key new groups, further research is needed to deepen our understanding of their drug use patterns, barriers to care, and specific needs. This knowledge will be essential for designing targeted interventions to prevent the escalation of high-risk drug use, improve access to care, and enhance health and social outcomes. Addressing these challenges is critical to safeguard public health and ensuring timely and effective responses to evolving drug use trends.

## Research priorities

Based on the study findings, several research priorities were identified. These are listed below in no particular order.

1. Characteristics of people using non-prescribed psychopharmaceuticals
    - What are the characteristics of this diverse group of individuals using non-prescribed psychopharmaceuticals? How do users obtain non-prescribed psychopharmaceuticals, including synthetic opioids? What factors influence the risk of health damage, dependence, and overdose within this group?

2. Health risks of chemsex beyond MSM groups
    - What are the most common health risks associated with chemsex in non-MSM groups? What factors contribute to risky substance use in this context? How can these health risks be mitigated?

3. Accessibility of opioid agonist treatment for Eastern European homeless individuals
    - To what extent are methadone programs accessible to Eastern European migrants living on the streets? What barriers limit their access to these treatments?

4. Controlled access and distribution of psychopharmaceuticals within asylum centres
    - How are psychopharmaceuticals obtained among asylum seekers in asylum centres? What are the prescription criteria and procedures? What factors influence the accessibility and regulation of these medications?

5. Accessibility of addiction care and harm reduction for non-Dutch speakers
    - How accessible are addiction care and harm reduction services for non-Dutch speakers, such as expats? What obstacles hinder their access to care?

6. Reaching and educating users of new psychoactive substances
    - How can users of new psychoactive substances - who have no contact with educational or support services - be more effectively reached with education and harm reduction programs?

7. Supporting young people who are homeless or in shelters, particularly with housing
    - How can stable housing opportunities be offered to young people who are homeless or in shelters? How well do low-threshold harm reduction programs meet the needs of young people, and how can these be improved?

8. Monitoring self-medication with psychedelics
    - What are patterns of self-medication with psychedelics among individuals with mental health issues? What guidance can be offered to address their needs?

9. Monitoring drug use in prisons and enhancing access to addiction care and harm reduction
    - How can drug use in prisons be effectively monitored? How can addiction care and harm reduction interventions be scaled up, so that they are available to all people in prison?

# General discussion of the OPAAK study

## Crack cocaine use appears more prevalent than opioid use

The OPAAK study provides two population size estimates (PSEs): people with high-risk opioid use (HROU), who may or may not also use crack cocaine, and people with high-risk crack cocaine use without high-risk opioid use (HRCCU-only). The HROU population is estimated at 13,300 individuals in 2023 and appears to be marginally smaller than in 2012 (14,300 individuals). In contrast, the preliminary PSE for the HRCCU-only population was 16,000 individuals in 2023 and appears to be larger than in 2008 (12,400 individuals). The total population of people with HRCCU (with or without opioid use) is estimated to be about 27,000 individuals.

Key challenges and limitations in PSE accuracy

Interpretation of these findings require caution due to significant uncertainties in the PSEs stemming from methodological and contextual challenges:

- *Assumptions of the Multiplier Method were not fully met:* The reliability of the Multiplier Method is limited by various factors. The LADIS data, used as the benchmark, has too many critical data gaps and inaccuracies to be able to perform reliable estimates (see Chapter 1). Moreover, issues encountered during participant recruitment may have introduced bias into the sample, affecting the validity of the multiplier (see Chapter 1 and Chapter 2 Part 1).
- *Possible inequity in access to care:* It is unclear whether all individuals in the target groups have an equal chance of accessing addiction care and, thus, of being in LADIS (a pre-requisite for a PSE). In theory, anyone in the Netherlands has the right to care – either through regular pathways or special arrangements. However, some subgroups such as migrants may struggle to access care.
- *Limited representativeness of the field sample:* Field samples may not be representative of the broader population. For example, HROU individuals with stable circumstances (e.g., in OAT, stable housing, no procurement crime) are less likely to be identified through field work, and may thus skew PSEs.
- *Small sample size for the HRCCU-only estimate:* The HRCCU-only PSE is based on a pilot study with a small sample size. Therefore it is only a preliminary estimate with limited reliability.

Cross-validation with other data sources

Despite these limitations, the PSEs align with broader trends observed in addiction care and other datasets from the OPAAK study and beyond, providing valuable insights into substance use patterns.

*Opioid use:* The decline in the HROU population mirrors the decrease in HROU patients registered in LADIS (from 12,313 to 9,630 patients between 2012 and 2023; Wisselink et al., 2024). It is important to note that underreporting to LADIS (see Chapter 1) likely amplifies the apparent decline in HROU patients, while the shift in OAT delivery to general practitioners may have lowered the in-LADIS rate, artificially inflating the HROU PSE. Considering these factors, the actual decline in the HROU population likely lies somewhere between the decreasing trends by the PSE and addiction care data. Additionally, the average age of HROU patients in LADIS is increasing, suggesting this group largely consists of an aging population (Wisselink et al., 2024). Also experts and field workers observed a stabilization or small decline in opioid users over the past decade.

*Crack cocaine use:* Several indicators underscore the high prevalence of crack cocaine use. Among the HROU group, nearly 90% also used crack cocaine, with most using it near daily (23 out of 30 days). The HRCCU-only PSE excludes these dual users because of the target group definitions used in this study. The total population of people with high-risk crack cocaine use is therefore much larger than the HRCCU-only PSE. Furthermore, a comparison to a previous study suggests a shift in the relative proportions of HROU and HRCCU-only individuals over the past decade. In 2012, HRCCU-only individuals were less prevalent than HROU individuals (Cruts & Van Laar, 2010). However, in 2023, field workers encountered many more HRCCU-only individuals compared to HROU individuals during recruitment. Finally, a rise in crack cocaine use was also reflected in qualitative observations from experts and field workers in the Netherlands, as well as trends in other European countries, such as Switzerland, Germany and France, indicating a broader regional trend (EUDA, 2024).

Thus, despite limitations of the PSE methodology, the data suggests that crack cocaine use is highly prevalent and plays a more prominent role now among vulnerable populations than a decade ago.

## Access to addiction care appears limited, especially for HRCCU-only individuals

The proportion of individuals in addiction care, as indicated by the in-LADIS rate, seems limited. Among HROU individuals, 61% were in addiction care in 2023, compared to 87% in 2008. People with HRCCU-only were even less in addiction care, with 31% in addiction care in 2023, compare to 41% in 2008 (Cruts & Van Laar, 2010). However, also these findings need to be interpreted with caution due to methodological limitations, such as possible differences in the representativeness of field samples.

Cross-validation with other data sources

Despite methodological limitations, the decline in the in-LADIS rates seems plausible when viewed alongside other data from the OPAAK study and field observations, and may be explained by the following factors:

- *Increase in people who were not born in the Netherlands:* According to expert observations, there is an increasing proportion of people using opioids and crack cocaine who are migrants. At the same time, data from our study shows that people who were born outside the Netherlands are less in addiction care than people born in the Netherlands. Non-Dutch individuals may struggle to access care due to unfamiliarity with the Dutch system and language barriers, although also Dutch nationals reportedly have difficulties navigating the addiction care system (see Chapter 4).
- *Limited addiction care for people using crack cocaine:* The low in-LADIS rate for the HRCCU-only population may reflect the limited availability of specialized addiction care services for people using crack cocaine. Specifically the absence of an effective crack cocaine agonist pharmacotherapy, comparable to OAT for opioid users, may exacerbate this issue.
- *Shift in opioid agonist therapy (OAT) prescription system:* The reduced in-LADIS rate for the HROU group may be partly explained by changes in the OAT prescription system. Experts reported that, in recent years, older and more stable OAT clients started receiving OAT from their general practitioner – many of whom do not report to LADIS. Data on the number of OAT clients at general practitioners is scarce.
- *Expert observations:* In the Trimbos Institute's Synthetic Opioids Preparedness Scan, various experts reported observing an increase in drug users who are not accessing care (JP. Kools, personal communication, March 2024).

Among HROU individuals, the proportion of people in addiction care remained stable in Amsterdam between 2012 and 2023, but was lower in the other recruitment cities. The stability in Amsterdam may reflect the ongoing outreach efforts of the Mainline Foundation, which operates in the city. These findings highlight the vital role that organizations like Mainline play in connecting drug using individuals to addiction care services.

Despite methodological limitations, the data suggests that the overall proportion of individuals in LADIS-registered addiction care has decreased over time. This may be due to several factors, including an increased proportion of migrants. It should be noted that if certain individuals, such as those not born in the Netherlands, face greater barriers in accessing care, this could result in an overestimation of PSEs.

## Population characteristics appear to have shifted

Characteristics of the HROU and HRCCU-only populations

The HROU and HRCCU-only populations share many similarities in characteristics and treatment outcomes, indicating that, in many ways, they belong to the same population. However, there are also important differences. HRCCU-only individuals were younger, more likely to be born outside of the Netherlands, more likely to reside in homeless shelter/night shelters, and less likely to stay in assisted living facilities than HROU individuals. They also engage less with addiction care (as indicated by the 'in-LADIS rate'), are less likely to use benzodiazepines, and less likely to go to drug consumption rooms (DCRs) compared to HROU individuals. The discrepancy in access to care was already identified in a study in 2008, with one potential explanation being the lack of an effective agonist pharmacotherapy for crack cocaine.

Access to DCRs in the Netherlands is often restricted to individuals already receiving addiction care at an organization. The low use of DCRs and high rates of paraphernalia sharing among HRCCU-only individuals underscores the need to reassess and adapt current DCR policies to improve access for people who use crack cocaine. DCRs play a critical role in harm reduction by providing clean drug paraphernalia, harm reduction advice, and often connecting users to additional supportive services, such as rest areas and hygiene facilities.

Changes in population characteristics

Experts and field workers have observed a growing proportion of migrants and undocumented individuals using opioids and crack cocaine in recent years. These groups are often in public spaces and low-threshold facilities, suggesting that they might have less access to addiction care. This could help explain the decrease in the in-LADIS rates and OAT coverage. However, since the proportion of migrants was not reported in the previous PSEs in 2008 and 2012, it is not possible to cross-validate these qualitative trend observations.

The HROU population continues to exhibit characteristics of an aging cohort, as evidenced by the increasing average age and low rate of first-time treatment entrants (Wisselink et al., 2024). While mortality among older individuals may contribute to this trend, an influx of migrants, as previously mentioned, may partially offset these losses.

In contrast, the characteristics of the HRCCU-only population appear to be changing. Approximately 75% of HRCCU-only participants had no history of high-risk opioid use, suggesting that this group largely represent a new population that did not transition from opioids to crack cocaine. Additionally, HRCCU-only individuals are generally younger and more likely to have been born outside the Netherlands compared to HROU individuals. Reports from other European countries indicate that the crack cocaine scene is increasingly characterized by antisocial and violent behaviour. Given the high cost of regular crack cocaine use, many individuals resort to drug dealing or petty crime to sustain their dependence. Although widespread reports of antisocial behaviour have not yet emerged in the Netherlands, this may only be a matter of time.

## Sharing of drug paraphernalia is prevalent and testing for HIV/HCV is low

About 12% of people with HROU had injected drugs in the past year. This rate is similar to levels reported a decade ago (13.2% IDU in the past 6 months; Cruts, Van Laar, & Buster, 2013) and lower than the 2022 EU average for first-time treatment entrants (18%; EUDA, 2024). Among people with past-year IDU, needle sharing was rare (2.2%). Most people had sufficient access to clean needles via Needle Syringe Programs (NSP, see Chapter 3). However, field workers reported seeing an increase in needles in public spaces in recent years. This raises the need for research to determine if the characteristics of injection drug users are changing, possibly with a rise in new users who might be unaware of NSP programs.

Alarmingly, the sharing of drug paraphernalia other than needles - such as crack pipes - was prevalent, with 63.8% of HROU individuals and 66.4% of HRCCU-only individuals reporting this behaviour in the past year. Sharing drug paraphernalia poses a risk of transmitting infectious diseases, but few people may be aware of this or underestimate the risk. This underscores the need for targeted harm reduction initiatives for those using crack cocaine.

Current medical guidelines recommend annual screenings for HCV and HIV among people who inject drugs (PWID) to mitigate health harms, reduce mortality, and prevent viral transmissions. However, fewer than half of PWID in the study sample had undergone HCV or HIV testing in the past year. This highlights critical gaps in adherence to screening recommendations and emphasizes the need to enhance outreach and access to testing for this population. Given the widespread sharing of drug paraphernalia beyond needles, expanding infectious disease testing to include non-injection drug users may be essential.

## Mental and physical health and quality of life seems poor

Around three-quarter of participants with HROU and HRCCU-only screened positive for depression and generalized anxiety disorder. This suggests that far more individuals could benefit from mental health treatment compared to the 16% currently receiving it.

More than half of participants reported physical health symptoms, such as dental problems, forgetfulness, trouble sleeping, and shortness of breath or difficulty breathing. A limitation of this assessment is that it focused on symptoms rather than medical conditions. For example, many participants reported having Chronic Obstructive Pulmonary Disease (COPD) but were not experiencing symptoms due to adequate medication. As a result, the true extent of health issues and disease burden may be underrepresented by the symptom

checklist. Despite this limitation, the findings highlight symptoms that are often overlooked in addiction care. Further research should explore ways to improve access to dental care and integrate support for managing symptoms, like forgetfulness, into care.

Quality of life ratings, which reflect overall satisfaction across various life domains (e.g. living situation, social relationships, physical and mental health, financial situation), were notably low among participants with HROU and HRCCU-only. The ratings were consistent with those of OAT patients in previous studies and significantly lower than those of the general population. Future research should examine strategies to enhance the physical and mental health and wellbeing of vulnerable people who use drugs.

### Opioid- and crack-using populations have unmet service needs

People using opioids and crack cocaine have various unmet service needs. First, the needs assessment revealed significant gaps in specialized addiction care, particularly for high-risk users of crack cocaine and older people with HROU. These groups are increasingly relevant given that opioid users are an aging population and that crack cocaine use is on the rise. Second, a prominent theme in the interviews was stigmatization and the impact it had on people's self-esteem, feelings of loneliness, willingness to seek help, and experiences in addiction care. This finding was supported by quantitative data from the questionnaire, where a large proportion of respondents reported discrimination from service providers and low levels of social integration. Addressing stigma and fostering social inclusion could play a critical role in supporting recovery from addiction. Finally, the interviews highlighted the need to expand outreach efforts. Various subgroups seem to struggle with accessing addiction care, such as HRCCU-only individuals and people who were not born in the Netherlands. This aligns with quantitative data from our study, showing that HRCCU-only individuals and those born outside the Netherlands are less in addiction care.

### Study limitations

The research has several limitations. First, there are uncertainties pertaining to the accuracy of the PSEs, as outlined above. The benchmark LADIS is not accurate and the field samples may not be fully representative of the broader populations. Moreover, the estimate of the HRCCU-only population is preliminary, because it is based on a pilot study with a small sample size. The pilot study was needed, as it was unclear at the start of the study how accessible and easy-to-reach the HRCCU-only population would be. Second, the data may be subject to self-reporting biases, such as recall bias, social desirability bias, or confirmation bias. For example, social desirability bias may have affected participants' self-reported recovery scores, which appeared unusually high. Third, misinterpretation of survey questions may have resulted in inaccurate responses. Some inconsistencies in responses across questionnaire items were identified. For instance, self-reported use of non-prescribed opioids may have included prescribed methadone, despite explicit instructions to exclude it. A similar issue was observed in the 2012 PSE study. Fourth, despite measures to prevent duplicate participation, such as using the same team of fieldworkers across cities, the possibility of some participants having taken part more than once remains. Given the anonymous nature of the study and the absence of identifying information, it was not possible to fully eliminate the risk of duplicate participation. However, field workers reported that the likelihood of this having happened was low.

## General conclusions

The findings from the OPAAK study reveal that while the size of HROU population appears slightly smaller than in 2012, the HRCCU-only population appears larger compared to the last PSE in 2008. Notably, a significant proportion of the HROU population also engages in high-risk crack cocaine use, meaning the total population of people with high-risk crack cocaine use is larger than indicated by the HRCCU-only estimate. The findings highlight the rising prevalence of crack cocaine use and its increasingly prominent role compared to opioid use within these vulnerable populations. Access to addiction care remains limited, especially for crack cocaine users who do not use opioids. Services tailored specifically for crack cocaine users are scarce compared to those available for opioid users. Given the stimulant properties of crack cocaine and its distinct patterns of use, there is a need for specialized interventions and services for this group.

More important than the absolute population sizes is the shift in demographic characteristics of these groups. A growing proportion of both the HROU and HRCCU-only populations comprises individuals who were not born in the Netherlands. Moreover, the HROU group largely represents an aging population with evolving needs, while the HRCCU-only group appears to be an emerging population with no prior history of high-risk opioid use. These demographic changes pose new challenges, emphasizing the need to reassess and adapt existing addiction care services to better address the evolving needs of these populations. Additionally, while needle sharing is rare, the frequent sharing of other drug paraphernalia, such as crack pipes, highlights the need for harm reduction strategies to prevent the transmission of infectious diseases.

As public health priorities evolve, so too must our approaches to care, ensuring they remain grounded in evidence, equity, and compassion. This study underscores the need for tailored, equitable, and inclusive addiction care policies in the Netherlands. Prioritizing accessibility, person-centred approaches, and responsive interventions is essential to addressing disparities in access to care and meeting the needs of these vulnerable populations.

# Recommendations

## 1. Improving the registration of addiction care in LADIS

Incomplete and underreporting of addiction care data to LADIS has significant implications. These gaps weaken the accuracy of population size estimates and obscure a clear understanding of the number of clients in addiction care and related trends in the Netherlands. To address these challenges, we propose several practical steps to improve the completeness of addiction care registration. Implementing these measures will strengthen LADIS as a more reliable system for monitoring addiction care, ultimately enhancing service delivery and informing better policy planning.

1.1 Enforce mandatory reporting of locations to LADIS

Although addiction care institutes are legally required to report the locations where patients receive care to LADIS (Wettenbank, 2024), this information is missing in practice. A comprehensive, up-to-date, readily-available overview of care locations would serve several purposes:

- *Enable quality control of LADIS data:* IVZ could identify which locations are underreporting data or failing to report data, ensuring more reliable oversight.
- *Support service need evaluation:* A complete location registration would help identify regional differences in service availability. For example, it seems that some regions in the Netherlands have no drug consumption rooms while others have barely any social shelters.
- *Support research:* National and international stakeholders, such as the EUDA, frequently request detailed overviews of drug consumption room locations and other service-related data. A centralized registry would facilitate the provision of such information.

The Netherlands could draw inspiration from registration systems and reporting policies from other countries, such as Germany, which operates a central registry of specialized addiction care facilities (see Chapter 1 #3).

1.2 Enforce mandatory reporting of opioid agonist therapy to LADIS

Despite being legally required, the reporting of opioid agonist therapy (OAT) data to LADIS is not enforced. Consequently, the number of OAT patients reported to LADIS is an underrepresentation. Data is missing from a number of sources, such as some addiction care institutes and general practitioners. In the past, the Netherlands had a centralized, comprehensive OAT registration system, but this was discontinued in 2012. This has left substantial gaps in knowledge about the number of OAT patients, the medications they use, and their treatment adherence. Enforcing OAT reporting to LADIS would improve monitoring of this critical patient population and enhance the accuracy of PSEs (e.g. Kraus et al., 2019). Best practices from countries like Germany, where OAT reporting is strictly enforced, could provide a valuable model (see Chapter 1, Finding 3).

1.3 Allocate resources to reduce registration burden and enhance IT system user-friendliness

Experts and stakeholders report that an increasing registration burden on staff, driven by time constraints and the growing volume of patient data that requiring documentation. The inefficiency and lack of user-friendliness in current IT systems exacerbate this issue, fostering resistance among healthcare professionals to

provide accurate and complete data entries. For example, the current system groups both cocaine and crack cocaine under a single category of 'cocaine', clarified only by a follow-up question asking whether the substance is snorted (powder cocaine) or smoked (crack cocaine). This design increases the risk of incomplete or missing data. Providing separate options for cocaine and crack cocaine at the outset would streamline data entry and improve accuracy.
Investing in resources to reduce the registration burden and improve the user-friendliness of IT systems would enhance data quality and encourage greater compliance with LADIS reporting requirements among addiction care institutes. Although IVZ is already engaging with stakeholders to address these challenges and improve data quality, additional resources and capacity are essential to effectively support these efforts.

## 2. Developing specialized services and interventions for people who use crack cocaine

The high prevalence of crack cocaine use in the Netherlands presents a significant public health challenge. In particular the group of people who use crack cocaine without concomitant opioid use appears larger than previously anticipated. However, insight into this population remains limited, as only a small proportion engages with addiction care services. To address this gap and enhance the uptake of care, we propose focusing on three key areas:

2.1 Specialized services for people using crack cocaine
Harm reduction and care services tailored specifically to people using crack cocaine remain scarce. Given the stimulant nature of crack cocaine and its distinct patterns of use, traditional services designed for opioid users may not be equally effective for crack users. Services may need to be designed to cater to the unique needs of this population. In addition, stable housing is a foundational requirement for effective and successful addiction care. Currently, over 40% of HRCCU-only individuals report living in shelters or sleeping on the streets. Implementing a 'Housing First' approach can provide the stability in people's lives which is necessary for further care and support. Lessons can be drawn from countries such as Switzerland, Germany, and France, where rising crack cocaine use has prompted the development of targeted responses (e.g. Stöver et al., 2023; Egli Anthonioz & Zobel, 2023). For instance, drug consumption rooms may be a key tool to deal with the rise in crack cocaine use (see below: recommendation #4).

2.2 Crack cocaine agonist pharmacotherapy
Emerging evidence from clinical trials for crack cocaine agonist pharmacotherapy – akin to OAT for opioids – is promising (Tardelli et al., 2020). However, additional research is necessary to evaluate its feasibility in real-world settings and its long-term efficacy. In this study, only very few participants reported using agonist pharmacotherapy for crack cocaine. Our needs assessment suggests that developing effective agonist medication for crack cocaine poses unique challenges. Unlike opioids, crack cocaine does not induce significant physical dependence, but rather psychological dependence. Crack cocaine does not need to be used daily; instead, its use often occurs in binge episodes (Roy et al., 2017). The growing prevalence of crack cocaine use underscores the urgent need for innovative and effective treatment options – not only for users in the Netherlands but also across other European countries.

2.3 Further research into people using crack cocaine
Our findings indicate that the majority of the HRCCU-only population has no prior history of high-risk opioid use, suggesting that this group emerged as a largely novel population, that did not transition from opioids to crack cocaine. Further research is needed to explore the origins and drivers of this population's growth, as well as its potential future trajectory. Understanding the demographic and behavioural characteristics of these individuals is essential for designing tailored interventions and services that effectively address their needs.

## 3. Enhancing access to addiction care

Many people who use opioids or crack cocaine face significant challenges in accessing addiction care. Data from the needs assessment indicates that many either lack knowledge about where to seek help or do not have the skills or resources to do so. People born outside the Netherlands are particularly underrepresented in addiction care, including OAT. Even though many individuals have Dutch health insurance and at least some proficiency in the Dutch language, they encounters barriers to accessing care. To address this gap, we recommend expanding targeted outreach efforts to underserved groups, including migrants, undocumented

individuals, and non-Dutch speakers. These groups often face challenges due to language barriers or unfamiliarity with the health care system. It is important to recognize that also Dutch nationals often face difficulties navigating the care system. Providing additional guidance and support to help individuals access addiction care services would benefit all who struggle to engage with the current system.

## 4. Enhancing access to drug consumption rooms, especially for people who use crack

Access to drug consumption rooms (DCRs) in the Netherlands is quite limited and often overly restrictive. Many DCRs restrict access to individuals who are already receiving services from an addiction care institute. This contradicts the intended role of DCRs as low-threshold facilities that are open to all people who use drugs. Beyond providing a safe space for drug consumption, a central goal of DCRs is to connect the most vulnerable individuals with additional care and support services.

Some regions in the Netherland appear to have no DCRs at all. A comprehensive overview is not available due to the lack of registration of service locations in LADIS. However, field workers from the OPAAK study corroborate these findings, reporting a significant shortage of DCRs and restrictive access policies at existing DCRs. Our research further supports these concerns, as 46% of HROU and only 31% of HRCCU-only individuals had accessed a DCR in the past year. These figures highlight potential barriers, particularly for people using crack cocaine and not opioids. Taken together, these findings suggest that current DCR policies in the Netherlands are insufficient to effectively engage vulnerable populations. Reevaluating the availability and accessibility of DCRs is critical to addressing these gaps.

Switzerland recognizes DCRs as a key tool in addressing the crack cocaine epidemic. To better support crack cocaine users, Swiss DCRs have integrated additional services, such as rest areas, hygiene facilities, laundry services, food provisions, and referrals to addition care and other support systems. Adopting similar adaptations in the Netherlands could significantly enhance the effectiveness of DCRs as a harm reduction strategy, particularly for the growing population of HRCCU-only individuals.

## 5. Scaling up harm reduction efforts for safer crack cocaine use

Our study found a high prevalence of sharing drug paraphernalia other than needles, such as crack pipes, among both HROU and HRCCU-only populations. This behaviour carries serious health risks, including the transmission of infectious diseases. To address this, we recommend strengthening existing harm reduction efforts aimed at promoting safer crack cocaine use. Measures include the free distribution of safer-use kits (including crack pipes) and targeted awareness campaigns that educate individuals about the risks of sharing paraphernalia and encourage safer practices. For maximum impact, these campaigns should feature culturally sensitive messaging tailored to the specific needs and behaviours of the target populations. Valuable lessons can be drawn from countries like Switzerland and France, which have been dealing with crack epidemics for some time. Incorporating best practices from these contexts could help improve harm reduction strategies in the Netherlands and ultimately improve health outcomes for people using crack cocaine.

## 6. Enhancing the utilization of mental health services

A high proportion of participants in our study screened positive for depression and anxiety; however, only a small fraction reported receiving mental health care. Considering the critical role of mental health in overall wellbeing and recovery, it is important to investigate the reasons behind this discrepancy and develop strategies to improve access to and utilization of mental health services. Approximately half of the participants reported having a smartphone with adequate internet access, suggesting an opportunity for eHealth interventions. Digital tools could provide innovative and accessible ways to support mental health and recovery efforts. In addition, targeted outreach efforts are recommended to connect individuals with appropriate care options. Outreach work plays a pivotal role in building trust, reducing barriers to care, and guiding individuals—particularly those who may be hesitant or unaware of available resources—towards mental health treatment, ultimately improving their access to essential services.

## 7. Tailoring services to meet the needs of the aging population of opioid users

The population of high-risk opioid users is aging. Despite services being available for them for decades, this group continues to face poor physical and mental health, limited social integration, and frequent discrimination at addiction care facilities. To address these challenges, it is essential to expand access to critical services, such as mental health care and dental care, to close existing treatment gaps. Efforts should also focus on reducing stigma and discriminatory attitudes among addiction care providers by implementing targeted interventions that foster a more supportive and inclusive environment. Additionally, reassessing the OAT coverage and developing strategies to improve access to OST are crucial steps. Finally, creating personalized treatment plans that are tailored to the unique needs of aging opioid users may significantly enhance recovery outcomes and improve overall wellbeing.

## 8. Implementing initiatives to monitor and respond to new trends in high-risk drug use

Emerging trends and new groups of high-risk drug users often go undetected by existing monitoring systems, delaying their identification . This study highlights nine concerning new trends and groups that require attention. Among these are the increasing use of non-prescribed psychopharmaceutical (such as synthetic opioids), the significant health risks associated with chemsex behaviours, and the barriers that migrants and other non-Dutch individuals face in accessing addiction care. Each of these trends carries unique health risks. Further research is needed to better understand these emerging and evolving drug use patterns. Interventions should be developed and implemented in a timely manner to prevent harms and reduce health risks. By addressing these challenges proactively, we can better safeguard vulnerable populations and lessen the overall burden on public health.

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## Appendices

# Appendix A. Questionnaire

## Onderzoek naar gebruik van opiaten en basecoke

**Stad**

- Amsterdam
- Rotterdam
- Den Haag
- Utrecht
- Eindhoven
- Haarlem
- Groningen
- Heerlen

**Locatie**

_____

**Werving**

Vragen:
• Gebruik je minstens 1 keer per week **opiaten** of **basecoke**?
• Of ben je in **behandeling** met methadon, buprenorfine of medische heroïne?

Doel:
• Inzicht krijgen in de gezondheid en het welzijn van mensen die opiaten en basecoke gebruiken.
• En kijken of de hulpverlening aan hun behoeften voldoet.

Belangrijkste informatie:
• Het interview duurt ongeveer **een half uur**.
• Je antwoorden zijn **anoniem** en worden vertrouwelijk behandeld.
• Je mag vragen **overslaan**. Als je op enig moment niet meer wil doorgaan, dan kun je stoppen.
• Na afronding van het interview krijg je een vergoeding van **10 euro**.

Check:
• Heb je al eerder meegedaan aan dit onderzoek?

**Consent form**

*Uitleg en toestemming vragenlijstonderzoek met mensen met risicovol gebruik van opioïden en crackcocaïne*

See other document

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**Screening vragen**

Ik wil je graag eerst een paar vragen stellen om te checken of je aan het onderzoek mee kunt doen.

**1. Ben je 18 jaar of ouder?**

- Ja
- Nee

If No, exclude.

**2. Heb je in de afgelopen 12 maanden <u>minstens 1 keer per week opiaten</u> gebruikt die je NIET op recept hebt gekregen?**
**Bijvoorbeeld heroïne/bruin, oxycodon of fentanyl.**
*- Wekelijks in minstens 6 van de afgelopen 12 maanden. (Dus ook als iemand een paar weken niets heeft gebruikt, kan hij/zij mee doen.)*
*- Alternatief: Gebruik je opiaten die je niet voorgeschreven krijgt/ die illegaal zijn/ die je niet van een arts krijgt?*

- Ja
- Nee

*Voorbeelden opiaten, zie hieronder:*

- Morfine (Oramorph®, Kadian®, Avinza ®)
- Codeïne
- Tramadol
- Oxycodon (OxyContin®, Oxynorm®, Percocet ®)
- Hydrocodon (Vicodin ®)
- Hydromorfon
- Oxymorfon
- Methadon, buprenorfine
- Fentanyl, carfentanil, acetylfentanyl, furanyfentanyl, ocfentanil
- Isotonitazene
- GEEN opiaten: kratom, Xanax, diazepam (Valium), xylazine (ook genoemd “tranq”)

>> Program the list of opioids as a drop-down menu.

**3. Ben je op dit moment <u>in behandeling</u> met methadon, buprenorfine, medische heroïne, of een andere heroïne-vervangende medicatie?**
*- Voorbeelden andere vervangende medicatie: morfine, codeïne, oxycodon, hydrocodone, etc.*
*- Alternatief: Krijg je deze middelen voorgeschreven vanwege je opiaatgebruik/ als vervanging voor heroïne?*

- Ja
- Nee

**4. Heb je in de afgelopen 12 maanden <u>minstens 1 keer per week basecoke</u> gebruikt?**
*- Wekelijks in minstens 6 van de afgelopen 12 maanden.*
*- Basecoke wordt ook crack, bori, of gekookte coke genoemd.*

- Ja
- Nee

Programming instructions:

- If Yes to #2 and/or #3, include the participant as HROU. (#4 is irrelevant to HROU).
- If No to #2 and #3, and yes to #4, include the participant as HRCCU-wo.
- If No to #2, #3, #4, exclude.

**5. Woon je langer dan 3 maanden in Nederland?**

- Ja
- Nee

If No, exclude.

Programming instructions: After the screening questions, all items are **non-mandatory**, except for **one** item: Section 'hulpverlening' item #2, because we need it for the in-LADIS rate.

## Algemene informatie

>> One response per question.

**1. Hoe oud ben je?**

- _____ jaar

**2. Met welk gender identificeer je je?**

- Man
- Vrouw
- Anders

**3. Wat is je geboorteland?**

*Zie onderaan deze pagina een kaart met EU-landen*

- Nederland
- Ander EU-land, namelijk: _____
- Niet-EU land, namelijk: _____

**4. Wat is het geboorteland van je moeder?**

- Nederland
- Ander EU-land
- Niet-EU land
- Weet ik niet

**5. Wat is het geboorteland van je vader?**

- Nederland
- Ander EU-land
- Niet-EU land
- Weet ik niet

>> Program this EU-map: https://european-union.europa.eu/easy-read_nl

**6. Wat is de hoogste opleiding die je afgerond hebt?**

- **Geen** opleiding/ **lager** onderwijs (basisschool)/ voorbereidend beroepsonderwijs
- Middelbaar algemeen voortgezet onderwijs (zoals **MAVO**, **VMBO**-g/t, (m)ulo, mbo-kort, mbo-1)
- Middelbaar beroepsonderwijs (zoals vakopleidingen bakker, mbo-lang, **MBO**-2/-3/-4, mts, meao)
- Hoger algemeen en voorbereidend WO (zoals hbs, mms, **HAVO**, **VWO**, atheneum, gymnasium)
- **HBO** – Hoger beroepsonderwijs (zoals kweekschool, hbo, hts, heao, hbo-v, bachelor WO)
- **WO** – Wetenschappelijk onderwijs (doctoraal of master, postdoctoraal, hbo-master)

**7. Heb je werk?**

- Ja, betaald werk. Aantal uur per week: ____
- Ja, vrijwilligerswerk/ stage
- Nee, met pensioen (AOW, prepensioen)
- Nee, arbeidsongeschikt (WAO, WAZ, WIA, Wajong)
- Nee, werkloos

**8. Wat is je huidige woonsituatie?**

*Hiermee bedoelen we: Waar slaap je 4 of meer nachten per week?*

- Huurwoning of koopwoning
- Logeren bij vrienden of familie
- Begeleid wonen
- Daklozenopvang/nachtopvang

- Op straat
- Anders, namelijk: _____

**9. Heb je een relatie?**
- Ja, we wonen samen
- Ja, we wonen apart
- Nee

**10. Heb je kinderen?**
- Ja
- Nee

**11. Heb je een Nederlandse zorgverzekering?**
- Ja
- Nee, maar ik heb een *andere* zorgverzekering
- Nee, ik heb *geen* zorgverzekering

If response to '#3 geboorteland' is non-EU, show this question:

**12. Heb je een verblijfsvergunning voor Nederland?**
- Ja
- Nee, in procedure/ asielzoeker
- Nee, ongedocumenteerd/ uitgeprocedeerd

## Hulpverlening

**1. Heb je de <u>afgelopen 12 maanden</u> gebruik gemaakt van de volgende hulpverlening of diensten:**

| | | Ja | Nee | Wil ik niet zeggen |
|---|---|---|---|---|
| a | Behandeling met methadon, buprenorfine, medische heroïne, of een andere heroïne-vervangende medicatie | O | O | O |
| b | Gebruikersruimte | O | O | O |
| c | Spuitomruil | O | O | O |
| d | Dagopvang/inloop | O | O | O |
| e | Nachtopvang | O | O | O |
| f | Woonbegeleiding | O | O | O |
| g | Budgetbeheer/ schuldhulpverlening/ bewindvoering | O | O | O |
| h | Arts of verpleegkundige | O | O | O |
| i | Maatschappelijk werk | O | O | O |
| j | Psychische hulp (bijv. therapie, psycholoog, psychiater) | O | O | O |
| k | Andere ondersteuning (bijv. case manager, buddy) | O | O | O |

**2. Heb je de <u>afgelopen 12 maanden</u> gebruik gemaakt van de hulpverlening of diensten bij de volgende locaties:**
*Dit is een belangrijke vraag!*
*Doorloop alle locaties, zodat deelnemers bij de volgende vraag alleen nieuwe locaties vermelden.*
- Ja
- Nee

>> Program the list of locations per city (depending on the first item 'stad'). This items is MANDATORY.

**3. Waar heb je de <u>afgelopen 12 maanden</u> nog meer hulp gekregen?**
*Noteer de naam en/of adres van de locaties. Zo krijgen we een beter beeld van de beschikbare hulpverlening.*
- _____

## Middelengebruik

**1. Heb je de volgende middelen in <u>de afgelopen 12 maanden</u> gebruikt, ook al was het maar 1 keer? Het gaat om het gebruik van middelen die je NIET op recept krijgt.**

| | | Ja | Nee | Wil ik niet zeggen |
|---|---|---|---|---|
| A1 | Heroïne (niet op recept) | O | O | O |
| A2 | Methadon (niet op recept) | O | O | O |
| A3 | Buprenorfine (niet op recept) | O | O | O |
| A4 | Oxycodon (niet op recept) | O | O | O |
| A5 | Tramadol | O | O | O |
| A6 | Fentanyl of carfentanil | O | O | O |
| A7 | Andere opiaten *(schrijf ze hieronder op)* | O | O | O |

Andere opiaten, namelijk: _____

If YES to any of the opiates (A1-A7), go to question 1.2 and 1.3:

**1.2 Hoe vaak gebruikte je opiaten (niet op recept) in de afgelopen maand?**
*Kies één van de opties:*

- Per week: _____
- Per maand: _____

**1.3 Hoe gebruikte je opiaten (niet op recept) in de afgelopen maand?**
*Meerdere antwoorden mogelijk.*

- Geïnjecteerd (slammen, shotten)
- Gerookt/ingeademd (chinezen, basen)
- Gesnoven
- Geslikt/gedronken (bommetjes, pilletjes)
- Anders, namelijk

>> Multiple answers possible.

**2. Heb je de volgende middelen in <u>de afgelopen 12 maanden</u> gebruikt, ook al was het maar 1 keer?**

| | | Ja | Nee | Wil ik niet zeggen |
|---|---|---|---|---|
| B | Basecoke (crack, gekookte coke) | O | O | O |
| C | Snuifcocaïne | O | O | O |
| D | Amfetamine (speed, pep) | O | O | O |
| E | Methamfetamine (crystal meth, ice, tina) | O | O | O |
| F | Benzodiazepinen/ benzo's (niet op recept!) (bijv. oxazepam, temazepam, lorazepam, diazepam) | O | O | O |
| G | Ketamine | O | O | O |
| H | GHB/GBL | O | O | O |
| I | Psychedelica (bijv. ecstasy, paddo's, LSD) | O | O | O |
| J | Cannabis (wiet, hasj) | O | O | O |
| K | Alcohol | O | O | O |
| L | Alpha-PVP (flakka) | O | O | O |
| M | 3-MMC of 3-CMC | O | O | O |
| N | Andere middelen *(schrijf ze hieronder op)* | O | O | O |

Andere middelen, namelijk: _____

Show 2.2 for each drug that is YES (B-M), except N:

**2.2 Hoe vaak gebruikte je <dit middel> in de afgelopen maand?**

*Kies één van de opties:*

- Per week: _____
- Per maand: _____

Show 2.3 only for basecoke + methamphetamine + 3-MMC/3-CMC:

**2.3 Hoe gebruikte je <dit middel> in de afgelopen maand?**

*Meerdere antwoorden mogelijk.*

- Geïnjecteerd (slammen, shotten)
- Gerookt/ingeademd (chinezen, basen)
- Gesnoven
- Geslikt/gedronken (bommetjes, pilletjes)
- Anders, namelijk

>> Multiple answers possible.

**3. Startleeftijd**

If YES to screening question #2 and/or #3 (opiaten/ behandeling opiaten):

**Hoe oud was je toen je voor het eerst opiaten gebruikte?**

___ jaar oud

If YES to screening question #4 (basecoke):

**Hoe oud was je toen je voor het eerst basecoke gebruikte?**

___ jaar oud

'Ever opioids' – only show these items for crack-only participants:

Heb je in het verleden ooit regelmatig (wekelijks of vaker) opiaten gebruikt?

- Ja
- Nee

  Als JA:
  Hoe lang gebruikte je regelmatig opiaten? _____
  Hoe lang geleden ben je gestopt met het regelmatig gebruik van opiaten? _____

Heb je ooit opiaat onderhoudsbehandeling gekregen (dus methadon, buprenorfine, medische heroïne)?

- Ja
- Nee

  Als JA:
  Hoe lang kreeg je opiaat onderhoudsbehandeling? _____
  Hoe lang geleden ben je gestopt met de opiaat onderhoudsbehandeling? _____

## Injecterend drugsgebruik en risicovol gedrag

**1. Heb je in de afgelopen 12 maanden een middel geïnjecteerd dat niet was voorgeschreven om te injecteren?**
*Let op: medische heroïne kan worden voorgeschreven voor injectie en telt dus niet mee.*
*Ook als de deelnemer maar 1 keer heeft geïnjecteerd (niet-voorgeschreven), kies JA.*

- Ja
- Nee

If YES, show items #2 - #5 (including the underlined instructions).
If NO, show only item #3 (excluding the underlined instructions).

De volgende vragen gaan over het delen van gebruikte naalden of andere hulpmiddelen.

**2. Heb je de afgelopen 12 maanden naalden met iemand gedeeld?**

- Ja
- Nee

**3. Heb je de afgelopen 12 maanden materiaal met iemand gedeeld, zoals spuiten, filter, watten/katoen, basepijp, rietje, snuifbuis.**

- Ja
- Nee

**4. Ben je de afgelopen 12 maanden getest op hepatitis C?**

- Ja
- Nee
- Weet ik niet

**5. Ben je de afgelopen 12 maanden getest op HIV?**

- Ja
- Nee
- Weet ik niet

## Gezondheid

De volgende vragen gaan over je gezondheid.
Programming instructions: Don't program the headings in light gray.

Lichamelijke gezondheid

Heb je de volgende klachten:

| | Ja | Nee | Wil ik niet zeggen |
|---|---|---|---|
| Kortademig/ moeite met ademhalen | O | O | O |
| Aanhoudende hoest | O | O | O |
| Pijn op de borst | O | O | O |
| Hart fladderen/hartkloppingen | O | O | O |
| Abcessen/ infecties als gevolg van injecteren | O | O | O |
| Darmproblemen/ diarree/ constipatie | O | O | O |
| Slaapproblemen | O | O | O |
| Tandproblemen | O | O | O |
| Dingen vergeten | O | O | O |
| Anders, namelijk (noteer het hieronder) | O | O | O |

Andere gezondheidsklachten (aandoeningen of symptomen): _____

Depressie en angst

**Hoe vaak heb je de afgelopen <u>2 weken</u> last gehad van…**

| | | Helemaal niet | Een paar dagen | Meer dan de helft van de dagen | Bijna elke dag |
|---|---|---|---|---|---|
| 1 | Weinig interesse of plezier om dingen te doen | 0 | 1 | 2 | 3 |
| 2 | Je somber, depressief of hopeloos voelen | 0 | 1 | 2 | 3 |
| 3 | Je nerveus, angstig of gespannen voelen | 0 | 1 | 2 | 3 |
| 4 | Niet kunnen stoppen met piekeren of je zorgen maken | 0 | 1 | 2 | 3 |

Overdosis

**Heb je in de afgelopen 12 maanden een overdosis gehad waarbij je vreesde voor je leven of je gezondheid?**

- Ja
- Nee

If Yes:
Hoeveel overdoses heb je de afgelopen 12 maanden gehad? _____
Hoe vaak had je medische hulp nodig? _____
Met welke middelen heb je een overdosis gehad? _____

## Behandeling

Programming instructions:
- If HROU (based on screening questions), show items on opiates + basecoke + psychosocial.
- If HRCCU-wo (based on screening questions), show items on basecoke + psychosocial.

One response per item.

**Behandeling opiaten**

**1. Ben je in <u>behandeling</u> met methadon, buprenorfine, medische heroïne, of andere heroïne-vervangende medicatie?**
- Ja
- Nee

If Yes, continue. If No, go to section basecoke.

**1.1 Welke <u>opiaat-medicatie</u> krijg je?**
- Methadon
- Buprenorfine (bijv. Subutex, Suboxone)
- Medische heroïne/diamorfine
- Anders, namelijk _____

**1.2 Neem je deze medicatie <u>op locatie in</u>?**
*Alternatief: Waar slik je de medicatie?*
- Ik neem het altijd op locatie in (onder toezicht).
- Ik krijg het regelmatig mee naar huis.

**1.3 <u>Wie</u> schrijft je deze medicatie voor?**
- Mijn huisarts
- Iemand anders (bijv. verslavingsarts)
- Weet ik niet

**1.4 Hoeveel jaar ben je al <u>in behandeling</u> met methadon/ buprenorfine/ medische heroïne/ anders?**
*Als er een (lange) onderbreking was in de behandeling, haal die periode er van af. Tel verschillende medicaties bij elkaar op.*
- ____ jaar

**De volgende 5 vragen gaan over jouw ervaring met deze behandeling.**
*Geef een cijfer van 1-10: (1 = heel slecht, 10 = heel goed)*
>> Program a 10-point scale.

**1.5 Hoe goed stopt de medicatie je <u>trek</u> naar opiaten?**
**1.6 Hoe goed kun je <u>functioneren</u> met de medicatie?**
**1.7 Hoe tevreden ben je over <u>de arts</u> die je deze medicatie voorschrijft?**
**1.8 Hoe tevreden ben je over degenen die de medicatie <u>afgeven</u>?** (Bijv. verpleegster, apotheker)
**1.9 Hoe tevreden ben je over de <u>locatie</u> waar je de medicatie inneemt of afhaalt?** (Bijv. openingstijden, wachttijd, fysieke locatie)

**Behandeling basecoke**

**2. Krijg je medicatie ter vervanging van basecoke? (We bedoelen: medicatie voorgeschreven door een arts.)**
*Bijv. dextroamfetamine/dexamfetamine, gemengde amfetaminezouten, bupropion, modafinil, topiramaat.*

- Ja
- Nee
- Niet van toepassing. Ik gebruik geen basecoke.

If Yes, continue. If No, go to section psychische problemen.

**2.1 Welke medicatie krijg je?**

- Dextroamfetamine/dexamfetamine
- Gemengde amfetaminezouten
- Bupropion
- Modafinil
- Topiramaat
- Anders
- Weet ik niet

**De volgende 3 vragen gaan over jouw ervaring met deze behandeling.**
*Geef een cijfer van 1-10: (1 = heel slecht, 10 = heel goed)*
>> Program a 10-point scale.

**2.2 Hoe goed stopt de medicatie je <u>trek</u> naar basecoke?**
**2.3 Hoe goed kun je <u>functioneren</u> met de medicatie?**
**2.4 Hoe tevreden ben je over <u>je arts</u> die je deze medicatie voorschrijft?**

**Behandeling psychische problemen**

**3. Ben je in behandeling voor psychische/mentale klachten? Bijvoorbeeld bij een psycholoog, psychiater of in therapie (alleen of in een groep).**

- Ja
- Nee

If Yes, continue . If No, go to next section.

**De volgende 2 vragen gaan over jouw ervaring met deze behandeling.**
*Geef een cijfer van 1-10: (1 = heel slecht, 10 = heel goed)*
>> Program a 10-point scale.

**3.1 Hoe <u>tevreden</u> ben je met deze behandeling?**
**3.2 Hoe <u>nuttig</u> is deze behandeling?**

## Kwaliteit van Leven

**De volgende vragen gaan over je kwaliteit van leven.**
*Geef een cijfer van 1-10: (1 = heel slecht, 10 = heel goed)*

1. Hoe goed vind je op dit moment je **kwaliteit van leven** als geheel?
2. Hoe tevreden ben je met je **woonsituatie**?
3. Hoe tevreden ben je met je **lichamelijke gezondheid**?
4. Hoe tevreden ben je met je **psychische gezondheid**?
5. Hoe tevreden ben je met je **sociale relaties**?
6. Hoe tevreden ben je met je **dagelijkse bezigheden**?
7. Hoe tevreden ben je met je **financiële situatie**?

## Drugsgebruik

**Wil je je drugsgebruik op dit moment veranderen?**

- Nee
- Minderen
- Stoppen
- Meer gebruiken

## Internet toegang

**Heb je een smartphone met toegang tot genoeg internet?**

- Ja
- Nee

## Online drugsmarkten

**Heb je de afgelopen 12 maanden drugs online gekocht?**

- Nee
- Ja, van het Dark Web/Dark Net (hiervoor heb je speciale software nodig, bijv. Tor Browser)
- Ja, van Webshops/ het gewone Internet (dit kun je vinden met een normale zoekmachine, bijv. Google)
- Ja, anders (bijv. sociale media, fora)

>> Multiple answers possible.

## Integratie en discriminatie

**Vind je dat je meedoet met de samenleving?**

- Helemaal niet
- Een beetje
- Voor een deel
- Grotendeels
- Helemaal

**Hoe vaak voel je je gediscrimineerd door hulpverleners? Hiermee bedoelen we: Hoe vaak voel je je slecht of met weinig respect behandeld.**

- Nooit
- Bijna nooit
- Soms

- Vaak
- Altijd

## Herstel

**In hoeverre ben je het eens met de volgende stellingen:**
*Geef een cijfer van 1-10: (1 = helemaal niet mee eens, 10 = helemaal mee eens)*

1. Ik voel me gesteund door andere mensen.
2. Ik heb hoop en dromen voor de toekomst.
3. Ik voel me goed over mezelf.
4. Ik doe dingen die voor mij van belang zijn.
5. Ik voel dat ik controle over mijn leven heb.

---

If YES to injecterend drugsgebruik (page 6), show: 'injecterend drugsgebruik'. If NO, go to 'einde'.

## Injecterend drugsgebruik

We zijn bijna aan het einde. Je zei eerder dat je drugs injecteert. Mag ik je daar nog een paar vragen over stellen?

- Ja
- Nee

If Yes, show items below. If No, show 'Einde'

**Hoe vaak injecteer je?**
*Denk aan: gemiddeld over de afgelopen 12 maanden*
*Kies één van de opties:*

- Per dag: _____
- Per week: _____
- Per maand: _____
- Per jaar: _____

*Als het injectiepatroon gedurende het jaar verschilde, beschrijf dit hier, zodat het gemiddelde later kan worden berekend:* _____

**Waar heb je de <u>afgelopen 12 maanden</u> je schone naalden gehaald?**
*Meerdere antwoorden mogelijk.*

- Verslavingszorg, spuitomruil, of gebruikersruimte
- Apotheek
- Een vriend of kennis
- Het internet
- Anders, namelijk: _____

For each source of needles, ask these questions:

**<u>Hoe vaak</u> haal je schone naalden bij < bron >?**
*Kies één van de opties:*

- Per dag: _____
- Per week: _____
- Per maand: _____
- Per jaar: _____

**<u>Hoeveel</u> schone naalden haal je daar per keer?**

- ____

*Als het antwoord gedurende het jaar verschilt, beschrijf dit hier, zodat het gemiddelde later kan worden berekend:* _____

---

## Einde

**Dit is het einde van de vragenlijst. Is er nog iets dat je wilt toevoegen of zeggen?**

_____

**Meedoen aan vervolgonderzoek**
<u>Stel deze vraag alleen als je denkt dat de deelnemer gemotiveerd is om bij te dragen aan een discussie.</u>

We doen later nog een vervolgonderzoek. Daarvoor organiseren wij kleine groepen.
We willen dan graag horen wat je van de zorg en hulpverlening vindt en hoe je de hulpverlening zou verbeteren als jij dat mocht bepalen.

Het groepsgesprek duurt **1 uur en je krijgt hiervoor 20 euro.** Van het groepsgesprek wordt een opname gemaakt. Na het groepsgesprek wordt de opname uitgewerkt in een **anoniem** verslag en wordt de opname verwijderd, zodat gegevens niet meer naar jou herleidbaar zullen zijn.

**Heb je interesse om mee te doen?** Je kunt je contactgegevens achterlaten en dan nemen wij mogelijk contact met je op voor een afspraak. De antwoorden die je op deze vragenlijst hebt ingevuld blijven sowieso anoniem.

*Indien ja, vul de contactgegevens in de andere vragenlijst in ('Opaak contact').*

*Klik eerst op **'volgende'** om de gegevens van deze vragenlijst op te slaan!*

# Appendix B. Interview guide for the needs assessment

## OPAAK – Handleiding voor de Focusgroep

Needs assessment

## Inleiding

Hartelijk dank dat jullie willen meedoen aan deze focusgroep. Deze focusgroep hoort bij het onderzoek met de naam OPAAK. In dit onderzoek kijken we hoe het gaat met mensen die opiaten of basecoke gebruiken, en welke hulp ze zouden willen.

Het onderzoek wordt uitgevoerd door het Trimbos-instituut en Mainline.

- Mijn naam is [Naam] en ik ben een onderzoeker bij het Trimbos-instituut, bij de afdeling 'Drugs'.
- Dit is [Naam] en hij/zij is onderzoeker/veldwerker bij Trimbos/Mainline.

**Het doel van deze focusgroep is om te begrijpen of de zorg en het hulpaanbod aan de behoeften voldoet van mensen die opiaten of basecoke gebruiken.**
We willen graag van jullie weten wat jullie van het hulpaanbod vinden, en hoe deze verbeterd kan worden. Dit kan gaan om jullie lichamelijke en mentale gezondheid, maar ook om wonen, geld en andere hulp.

Wij hopen dat jullie informatie **helpt om de hulpverlening te verbeteren**.

- Er zijn geen goede of foute antwoorden. Wij zijn geïnteresseerd in jullie ervaringen en opvattingen.
- Deelname aan deze focusgroep is vrijwillig.
- Alle antwoorden worden vertrouwelijk behandeld. We schrijven geen namen of andere herkenbare informatie in het eindverslag.

- Het gesprek duurt ongeveer 1 uur.
- Je mag op elk moment stoppen met de focusgroep.
- Maar je moet tot het einde van de focusgroep meedoen om de 20 euro te ontvangen.
- We maken een geluidsopname, zodat we jullie antwoorden beter kunnen verwerken. Na het verwerken van de informatie worden alle geluidsopnames gewist.
- Hebben jullie nog vragen voordat we beginnen?

## Huishoudelijke regels

- Ga het gesprek aan met elkaar. Geef iedereen de kans om te spreken.
- Je hoeft niet je hand op te steken.
- Onderbreek elkaar niet, of doe dat anders op een beleefde manier.
- Zet je telefoon uit.

## Leg contact met de deelnemers

- *Stel jezelf kort voor:*
    - *Naam, leeftijd, achtergrond, werkervaring met mensen die drugs gebruiken, iets persoonlijks.*

- Kun je jezelf even voorstellen? (Of: Kun je kort iets over jezelf vertellen?)
    - *Naam, leeftijd, achtergrond (waar ben je opgegroeid?)*
    - *Hoe lang gebruik je opiaten/basecoke?, Ben je momenteel in behandeling?*
    - *(En wat voor andere informatie ze ook willen delen).*

## Vragen voor de Focusgroep

We hebben het vandaag over de zorg en hulpverlening.

- Dit kan de verslavingszorg zijn of elke andere vorm van hulpverlening.
- Ofwel waarvan je zelf gebruik hebt gemaakt of waarvan je hebt gehoord.
- Bijv.: methadonbehandeling, gebruikersruimte, opvang, woonbegeleiding, maatschappelijk werker

### 1. Wat vind je van de zorg en hulpverlening voor mensen die opiaten of basecoke gebruiken?

Sub-vragen: *(stel deze vragen altijd)*

- In het algemeen, wat voor **cijfer** geef je de zorg en hulpverlening? Van 1 *heel slecht* tot 10 *heel goed*.
- Aan **welke** zorg en hulpverlening denk je als je dit cijfer geeft?
- Wat is je **ervaring** daar mee? Positief en negatief.
- Wat gaat goed? En wat kan beter? – *zie prompts*
- *Optioneel*: Wat is er (nog zo) voor hulpaanbod in deze stad? Wat heb je daarover gehoord?

Prompts: *(suggesties, om de diepte in te gaan)*

- **Kwaliteit**: Hoe tevreden ben je over [de bestaande zorg en hulpverlening]?
- **Soort aanbod**: Op welke manier voldoet [het hulpaanbod] *niet* aan je behoeften?
- **Persoonlijk contact hulpverleners**: Wordt jij (of iemand anders) wel eens slecht behandeld?
- **Toegang**: Heb je ooit *geen* hulp kunnen krijgen? Waarom? // Wie krijgt geen hulp? Hoe komt dat?
- **Veiligheid**: Voelt het veilig? Waarom wel/niet?

### 2. Wat zou je aan de zorg en hulpverlening veranderen als jij het mocht bepalen?

Sub-vragen:

- Voldoet de beschikbare zorg en hulpverlening aan je behoeften? (Of: Waar is behoefte aan?)
- Wat moet er anders in de zorg en hulpverlening?

Prompts:

- **Kwaliteit**: Wat kan beter aan bestaande hulp?
- **Soort aanbod**: Welke steun zou je willen die er nu niet is? Wat voor hulpverlening ontbreekt?
- **Persoonlijk contact hulpverleners**: Wat kunnen hulpverleners anders doen?
- **Toegang tot zorg/hulp**: Wat zou het makkelijker maken om toegang te krijgen tot zorg?
- **Veiligheid**: Voelt het veilig? Waarom wel/niet?

### 3. Samenvattend: Dus [dit] is wat jullie vinden en [hier] is behoefte aan.

Klopt dit?

***

**Generieke vragen** (om onderwerpen te verdiepen):

- Kun je daar wat meer over vertellen?
- Wat vind jij daarvan? Hoe ziet dat er voor jou uit?
- Wat is er nog dat beter kan?

***Extra vraag:*** **Waar maak jij je zorgen over?** (Of: Wat zou je helpen om je kwaliteit van leven te verbeteren?)

| | |
|---|---|
| Lichamelijke gezondheid | Mentaal welzijn |
| Huis, geld, baan | Zelfbeschikking |
| Sociale relaties en steun | Discriminatie/stigma |

# Appendix C. Interview guide to assess new trends and groups of high-risk drug users

## OPAAK – Handleiding voor de Focusgroep

Nieuwe trends en groepen mensen met risicovol drugsgebruik

## Inleiding

Hartelijk dank dat jullie willen meedoen aan deze focusgroep. Deze focusgroep hoort bij het onderzoek met de naam OPAAK. In dit onderzoek kijken we hoe het gaat met mensen die drugs op een risicovolle manier gebruiken. Een van de doelen van dit onderzoek is om nieuwe groepen van gebruikers in kaart te brengen. Het onderzoek wordt uitgevoerd door het Trimbos-instituut en Mainline. Mijn naam is [Naam] en ik ben een [functie] bij Mainline. Dit is [Naam] en hij/zij is [functie] bij Mainline.

**Het doel van deze focusgroep is om nieuwe opkomende groepen van mensen die op een risicovolle manier drugs gebruiken in kaart te brengen.** Risicovol gebruik verwijst naar herhaaldelijk drugsgebruik, waarbij de persoon feitelijke schade oploopt, of een hoog risico loopt op dergelijke schade. Alhoewel verschillende monitors veranderingen in het drugsgebruik in de algemene bevolking kunnen vaststellen, worden kleinere groepen van gebruikers niet bereikt door deze monitors. Het is belangrijk om opkomende drugs-gerelateerde bedreigingen tijdig te signaleren, om tijdig te kunnen anticiperen op nieuwe risico's en de volksgezondheid te beschermen.

Graag horen we van jullie welke observaties jullie hebben gedaan in jullie dagelijks werk de **afgelopen vijf jaar** over nieuwe opkomende groepen van mensen die drugs risicovol gebruiken. Met deze informatie kunnen we aanbevelingen doen aan het Ministerie van Volksgezondheid, Welzijn en Sport (VWS) over het stellen van onderzoeksprioriteiten. Er zijn geen goede of foute antwoorden. Wij zijn geïnteresseerd in jullie observaties en opvattingen.

Deelname aan deze focusgroep is vrijwillig. Alle antwoorden worden vertrouwelijk behandeld. Wij zetten blanco naambordjes op tafel. Voor het gesprek is het handig als je je naam opschrijft. We schrijven geen namen of andere herkenbare informatie in de verslagen. Informatie in het eindverslag kan niet worden herleid tot jullie als persoon.

Jullie mogen op elk moment stoppen met deze focusgroep. Wij verwachten dat het gesprek ongeveer 60 minuten duurt. Als jullie daarvoor toestemming geven, dan maak ik graag een geluidsopname, zodat we jullie antwoorden beter kunnen verwerken. Na het verwerken van de informatie worden alle geluidsopnames gewist en we vernietigen ook alle aantekeningen die we tijdens de focusgroep hebben gemaakt.

Hebben jullie nog vragen voordat we beginnen?

## Hoe werkt een focus groep?

- Een kleine groep personen voert een gesprek en wordt begeleid door een moderator. Focusgroepen zijn nuttig om een probleem te verkennen en ideeën op te doen.
- Rol van de moderator en assistent: De moderator begeleidt de focusgroep en zorgt ervoor dat alle onderwerpen besproken worden. De assistent maakt aantekeningen en begeleidt de focusgroep waar het nodig is.
- De moderator zal de ideeën van groep samenvatten, voordat hij/zij verder gaat met het volgende onderwerp.
- Huishoudelijke regels:
    - Ga het gesprek aan met elkaar; geef iedereen de kans om te spreken.
    - Je hoeft niet je hand op te steken.

- Onderbreek elkaar niet, of doe dat anders op een beleefde manier.
- Zet je telefoon uit.

## Leg contact met de deelnemers

*Stel jezelf kort voor.*

- *Naam, achtergrond, rol in het OPAAK project, werkervaring met mensen die drugs gebruiken.*

*Vraag de deelnemers om zichzelf kort voor te stellen.*

- *Naam, duur en type ervaring in het werken met mensen die drugs gebruiken.*

## Definities

In deze focusgroep gebruiken we de definitie van risicovol drugsgebruik zoals voorgesteld door het Europees Waarnemingscentrum voor drugs en drugsverslaving (het EMCDDA):

- Risicovol drugsgebruik is 'herhaaldelijk drugsgebruik dat feitelijk schade toebrengt (negatieve consequenties) aan de persoon (waaronder afhankelijkheid, maar ook andere gezondheids-, psychische- of sociale problemen), of de persoon een grote kans/risico doet lopen om dergelijke schade op te lopen' (EMCDDA, 2013).

Voor het huidige onderzoek, wordt een **nieuwe opkomende groep van mensen met risicovol drugsgebruik** gedefinieerd als een onderscheiden groep die:

- Illegale drugs risicovol gebruikt, inclusief clandestiene of gelekte medicijnen of Nieuwe Psychoactieve Stoffen (NPS, designerdrugs);
- Is opgekomen of zichtbaar groter geworden in de afgelopen 5 jaar in Nederland; en
- Niet goed zichtbaar is in bestaande drug monitors (bijvoorbeeld de Gezondheidsenquête, of het Drugs Informatie en Monitoring Systeem (DIMS)).

## Vragen voor de Focusgroep

### 1. In de afgelopen 5 jaren, welke groepen van mensen met risicovol drugsgebruik zijn nieuw opgekomen of aantoonbaar in omvang toegenomen in Nederland?

*Prompts:*

- *Kenmerken van gebruikers, bijvoorbeeld land van herkomst; leeftijd; geslacht; behandelstatus; settingen van gebruik*
- *Gebruikspatronen, bijvoorbeeld type drugs, polygebruik, injecterend gebruik, wijze van toediening*
- *Type verandering, bijvoorbeeld nieuw opgekomen, significant toegenomen, lokale of landelijke ontwikkeling*

### 2. Waarin verschillen deze nieuwe gebruikersgroepen van bestaande groepen?

Sub-vragen:

2.1 Welke uitdagingen of zorgen zijn er rondom deze nieuwe gebruikersgroepen?
*Prompts:*

- *Waarom zijn de ontwikkelingen in deze groepen alarmerend?*
- *Welke schade en risico's worden verwacht?*

2.2 Waarom zijn deze nieuwe gebruikersgroepen mogelijk minder zorgelijk dan andere groepen?

2.3 Bereikt de bestaande zorg en hulpverlening deze nieuwe groepen en wordt voldaan aan hun behoeften?

### 3. Welke onderzoeksprioriteiten bevelen jullie aan voor de nabije toekomst met betrekking tot nieuwe gebruikersgroepen en waarom?

*Prompts:*

- *Welke gebruikersgroepen dienen prioriteit te krijgen en welke aspecten van deze groepen moeten te worden onderzocht?*
- *Welke informatie ontbreekt er over deze opkomende gebruikersgroepen?*
- *Wat zijn de risico's en mogelijke gevolgen als deze groepen niet worden onderzocht?*