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## Introduction

It is vital that people who are dependent on drugs or alcohol get the support they need to make a full recovery. Many substance misuse users will have experienced difficulties in life and are among the most vulnerable and marginalised in society due to the stigma of their addiction.

We wanted to find out if any improvements could be made to benefit service users by amplifying their voice so that their experiences could be shared and acted on by commissioners and service providers.

This report reflects comments from service users and staff. The findings reflect the qualitative side of the service, capturing service users' feelings and aspirations about recovery, alongside the practical day-to-day routine of running the organisation.

The recommendations made within this report include practical changes that can be made by the organisation as well as resourcing, contractual and delivery suggestions that could be driven by the commissioner.





## **Executive Summary**

### **Overview**

At Healthwatch Leicestershire we have pledged to gather the views of health and social care service users across Leicestershire. From May to June 2015 we collaborated with Swanswell, a national alcohol and drug charity that delivers services locally, to listen to both staff and service users to better understand their experiences of working within and accessing substance misuse services.

It is important to note that some of the experiences and suggested improvements shared with us fell outside the remit of Swanswell and into the wider health system, where different stakeholders hold varying responsibilities. However, from a service user perspective, they often see the system as a whole and are focused on their own coordinated journey of care.

Swanswell is committed to continuous improvement of their organisation and welcomed the opportunity to work with Healthwatch Leicestershire.

This report provides a narrative of the views, opinions and experiences of conversations with Swanswell staff and service users.

### **Aims**

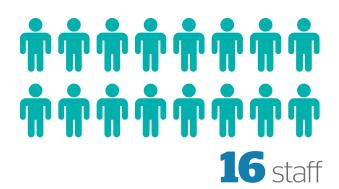
Our aim was to collect evidence and insight by listening to service users and staff so that we could:

- Establish a deeper understanding of service users' experiences.
- Understand what changes service users would make to improve their experiences with Swanswell.
- Gather the staff perspective on improvements.

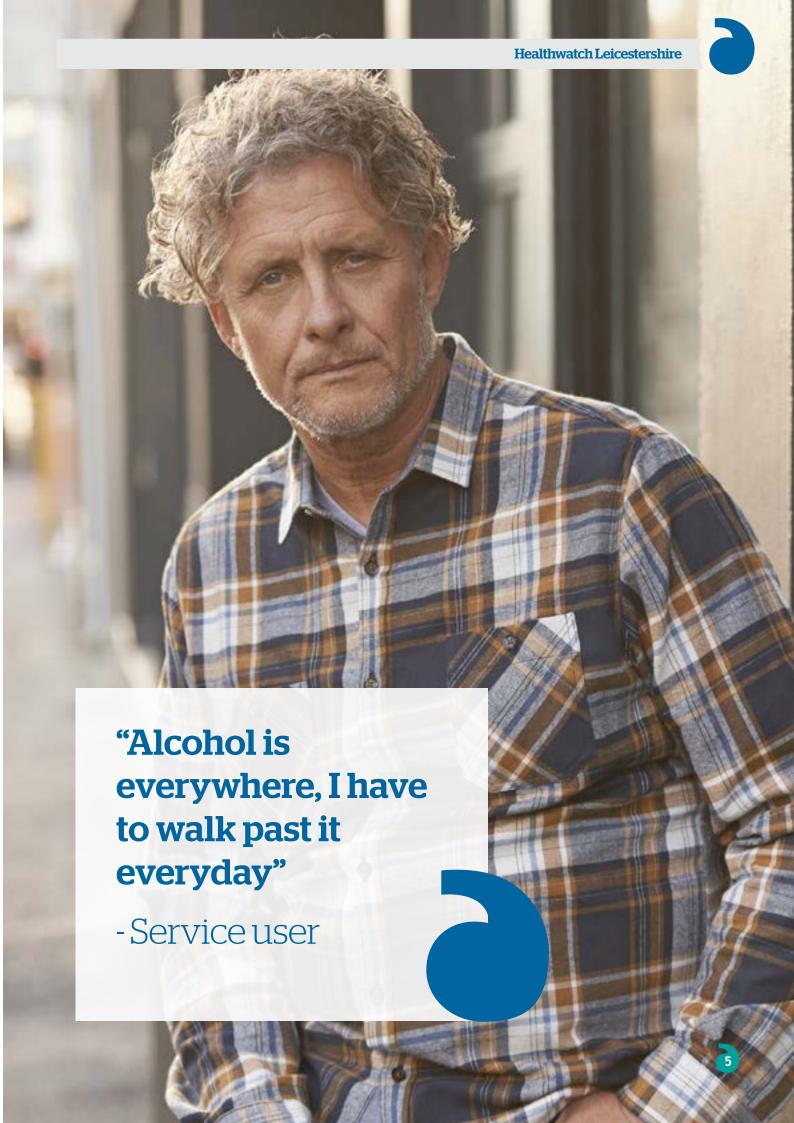
### We spoke to:



15 service users at Peer Mentor Groups



**51** service users completed a recovery survey



### **Emerging Themes**

### Service users

### Coordination of services

Services users spoke of a lack of a joined-up approach and co-ordination of care between different services or professionals. Links between GPs, hospitals and Swanswell regarding their care could be improved. Service users wanted professionals to treat them holistically, taking the whole person into account, dealing with their mental, social and physical illnesses.

### **Peer groups**

Support groups at Swanswell worked very well according to service users. We were told that a recovery plan that supports the user to think about the wider objectives of their recovery and lifestyle would be beneficial.

#### **Aftercare**

Aftercare could be put in place for those users who had left the service or were deemed to no longer need the service. They could receive a follow up appointment or conversation after a particular period of time.

#### **Access**

Offering services with joined up service provision at various locations outside of the city would offer users greater flexibility and access.

Service users felt attending more than one meeting a week would provide additional opportunities for support and aid recovery.



### **Emerging Themes**

### Staff

### **Manageable caseloads**

Staff said that more manageable caseloads would help to provide a healthier working environment, increase support and allow more dedicated time for clients.

### **Streamlined processes**

Reviewing and streamlining processes to avoid duplication of paperwork between various personnel would help to reduce administration and save time.

### **Ways of working**

Staff would welcome more time to discuss how to work smarter and review the practicalities of current working patterns and geographical locations of staff across Leicestershire.

## Common themes from service users and staff

- Improve access to services across Leicester and Leicestershire
- Better communication across health professions and locations
- One stop shop for support





## **Recovery Survey**

### Findings

We designed a survey to allow service users who did not regularly attend the groups, or attended groups we did not visit, to also be part of this insight project. The following issues emerged from survey respondents.

#### 1. Other Services

37% of service users reported that there is something else that could help them with their recovery that is not already being offered, namely:







Aftercare

**Transport** 

**Activities** 

### 2. Motivation for Recovery

**92%** of respondents told us that the following motivated their recovery:



**Family Contact** 





Possibility of a



**Peer Support** 

### 3. Additional Support

**20%** of respondents felt there was nothing that could be offered as additional support in other areas to help their recovery. Service users were provided with the following options of support and asked if they would potentially be helpful to their recovery. More than one option could be chosen.



Mental Health 56%



Housing 30%



**Employment 16%** 



Financial 28%



Other 4%



### Recommendations

Based on our findings, Healthwatch Leicestershire offers the following recommendations to providers and commissioners of services:

## **Leicestershire County Council**

- To use the findings of the report to help inform future procurement and commissioning of substance misuse services.
- 2. Substance misuse should be understood as a period of illness affecting the body and mind, developed as part of a public health campaign which may help to reduce the stigma service users feel and experience.

### Swanswell and Leicestershire County Council

3. To use the findings of the report as a springboard to further understand what is of most benefit to service users.

#### **Swanswell**

- 4. Implementation of a recovery plan that sets out the service user journey with their progress and next steps, reflecting an understanding of the different individual needs. This would include their aims, how they will be supported to achieve the plan and would provide a continued journey through the system.
- A patient's aftercare plan should be recognised as an important step in maintaining the will to stop substance misuse for service users. It would also be useful to have a follow-up conversation built into the service, to allow contact to be made with the ex-service users at the three to six months' stage to assess whether additional support is needed. This would be beneficial especially for those with no support system at home.
- 6. Review the provision of peer support groups/ meetings to either continue to develop these or create new activities that further benefit the recovery of service users.

### Clinical Commissioning Groups and Better Care Together partners

- A system that flags to a GP when a substance misuse service user has not collected their repeat prescription could be explored (considering any patient consent issues), as not taking medication could be detrimental to recovery.
- 8. Greater links and understanding between hospitals and substance misuse services to better support the user should be adopted. These links would be beneficial to all parties and be a step forward in terms of risk management. To set out and implement a clear pathway of communication between emergency services when a patient is identified or admitted for a drug or alcohol issue, as working with Swanswell would be both beneficial and expedient.





## **Main Report**

### **Overview**

### Background to Swanswell

Swanswell is a national alcohol and drug charity created in 1968 that helps people to change their lives. They believe in a society free from problem alcohol and drug use. Swanswell help more than 9,000 people per year overcome problem alcohol and drug use through face-to-face interventions and has reached over 100,000 people online in 2013/14.



Swanswell Supports

1500

per year across Leicestershire and Rutland



Swanswell provides

12

Service user forums, family/ carers groups and peer mentor groups locally

## National and local context

Services that support people to recover from substance misuse can often be seen as lifesavers to their users. In addition, these services can reduce the costs to tax payers and the overall health of people across the country.

According to a report by The Centre for Social Justice 'No Quick Fix' the cost of alcohol abuse to taxpayers is £21 billion a year, followed by drugs at £15 billion per year, with 1.6 million people dependent on alcohol in England alone.

Public Health England has reported that alcohol is the third biggest risk factor for illness and death in England and that 1.2 million people are affected by drug addiction.

The local Swanswell service in Leicestershire and Rutland started on 1 July 2011 and now operates out of two offices based in Coalville and Loughborough as well as from district based hubs across the two counties. They work in GP surgeries providing shared care. Swanswell supports approximately 1500 service users each year in Leicestershire and Rutland and accepts referrals from a variety of sources but mainly from either GP's or self-referrals.

This report provides a summary of what service users and staff told us when we visited Swanswell.



## Methodology

The project involved various components to gather staff views and service user experiences. First, an initial introduction took place with Swanswell where we agreed an approach to access service users and staff.

### **1** Group Discussions

We attended four peer mentor focus groups across Coalville, Oadby & Wigston and Hinckley, allowing open conversation and a chance to share experiences.

6 May - Coalville



8 May - Wigston



20 May - Hinckley



21 May - Coalville



#### 2 Recovery Survey 3

The survey captured new and existing service users through drop-in sessions, reception waiting areas and outreach locations.



51 responses

#### Staff Feedback

We offered staff an opportunity to tell us what changes, if any, they would make to the service, that would allow them to provide better care to service users.



Healthwatch Leicestershire attended peer mentor focus groups in Coalville, Wigston and Hinckley



### **What Service Users told us**

### Peer mentor groups

These groups are an opportunity for users to provide each other with support and talk about their feelings, experiences or needs. We spoke to service users at peer mentor focus groups with existing service user forums.

We asked if they could change anything about the service they received, what it would be. The information was then analysed and grouped into common themes. Due to the small size of the groups we have not shown the location of the service user within quotes to preserve their identity.

This is what service users told us about their experiences:

#### Coordination

Once referred to Swanswell by their GP, several users felt unsure whether to attend their GP or visit Swanswell. They expressed concern that, through no fault of their own, their GPs may not be the best health professional to understand their mental and emotional state. However, some users felt that once they had been referred to Swanswell, the relationship with their GP deteriorated.

- Some users that had been discharged from a hospital setting, after being admitted as a result of substance misuse, commented that they had not been asked if they needed any support or if they were currently accessing substance misuse services.
- We were told that, currently, residents of Leicestershire could not access services in Leicester. For some, not being able to use cross-border services may discourage them from accessing services altogether. In addition, new service users who may want to attend with a friend or use cross border services fearing stigma, would not be able to receive support.

"GPs need to be more understanding about alcoholism"

- Service user



### Peer mentor groups

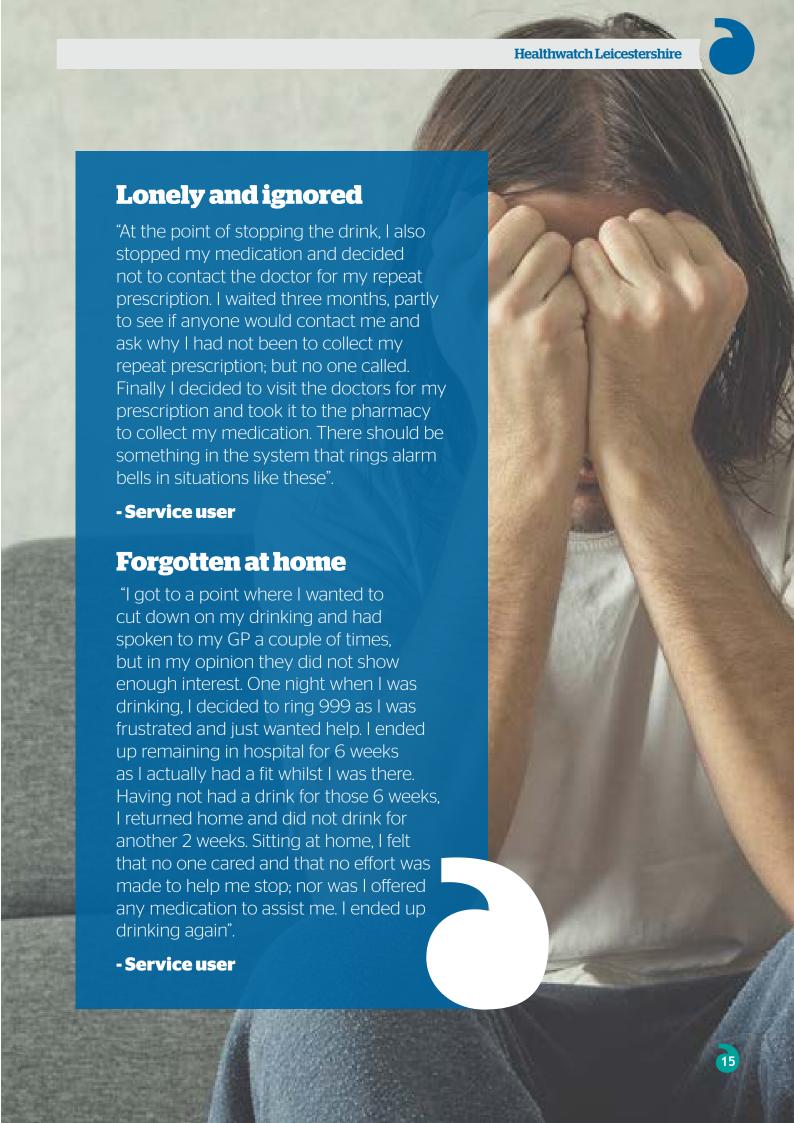
#### **Care and Support**

- Users said that when they were drinking, they would be more prone to miss taking their medication. One person who was on a repeat prescription told us that they waited three months before going back to the GP to get their prescription. During this period no one made contact about medication.
- When users had stopped taking drugs or alcohol, they commented that their journey was only part way and that after care could play a big part in their decision to stay clean and motivated.
- Promotion of the various types of support services that are available to users of the service would be useful. Users were not aware that they may have been able to access additional support such as help finding employment, volunteering opportunities or housing.

- Some service users would benefit from a structured recovery plan that supports them with their recovery and encourages them to make positive decisions about their life. This could also include their aspirations for where they would like to be in the future.
- Users suggested the introduction of aftercare so those who had left the service or been deemed to no longer need it, would receive a follow up appointment or conversation after a particular amount of time.
- Some service users who are on their own or have limited support systems often struggle at weekends or in the evenings, which is their most vulnerable time. Being involved in regular evening activities may be helpful to their recovery. Opportunities that encourage service users to build relationships and try new activities could be beneficial and worth investment.

"Even when you stop drinking, the symptoms of feeling low are still there. Its as if you are still in the same mind set but without the drink"

- Service user





### Peer mentor groups

#### Access

- Some service users would access services in a different location to where they reside to avoid people knowing they go to Swanswell. This was something that several service users mentioned.
- Service users also mentioned that they felt stigmatised for using substance misuse services and that this could deter other people from accessing services when they need them most
- We were told that an out of hours helpline run by Swanswell that could be accessed at weekends would be useful. This is when there is limited support available, especially in particular areas.
- Drop in sessions take place in:
  - Coalville Monday to Friday 9am 5pm (Thursdays until 7pm)
  - Loughborough Monday to Friday 9am -5pm (Thursdays until 8pm) and Saturday 9am - 2pm
  - Open all bank holidays
- Service users who did not reside in those areas could not access these locations without difficulty.
- Service users spoke about wanting more than one support group meeting a week. They also mentioned that on occasion the group could be cancelled due to staff training, holidays or sickness. These times were particularly difficult as service users would have to wait two weeks before attending the support group.

- Service users told us that they would benefit from structured day support services as they encouraged them out of the home and allowed them to take part in an activity. It was suggested that free or low cost activities could be organised in order to manage the financial pressure on the service. Sessions such as first aid courses and gardening using allotments were mentioned. Service users thought that this would provide a distraction to their daily struggle of recovery.
- We were told that certain medications prescribed by GPs to help users cope with reducing alcohol levels could only be provided once the service user's alcohol intake had already lowered. Service users felt that this was a catch 22 as the actual medication that could help them could not be given until they somehow started to deal with the issue without medication.

"Although I access the Swanswell services, I don't tell anyone because I don't want to be judged"

- Service user





### All about Recovery - Survey

We designed a survey to allow service users that do not regularly attend the groups to also be part of the process. The following issues were captured by the survey:



51
service users completed our survey.

"Attending the group peer mentor sessions gives me an incentive not to drink"

- Service user

#### **Question 1:**



service users (19 out of 51) reported that there is something else that could help them with their recovery that is not already being offered.

- At times, service users felt that once they were on the right track and had stopped drinking, they had been left to find their way alone. A more organised after-care for service would be beneficial.
- Transport options that allowed service users to be picked up from their home would encourage them to attend more frequently. It would also encourage some users not to drink at those specific times as they would be aware of their peers and workers collecting them and would not want to let them down.
- Several users commented that emotional support at times when they felt most vulnerable, or when they had not attended peer support sessions, was an important element to the service. In addition to this, users mentioned that receiving a phone call from their peer support worker at those times would help make a difference to their mood.
- We were told that activity groups that encouraged service users out of the home and into social environments would help to reintroduce them into society.
- Service users told us that they would like to see more groups across different geographical locations of Leicestershire, particularly in Harborough and Hinckley.



#### **Question 2:**

92% of respondents (47 out of 51) told us that the following motivated them with their recovery.

- Many service users that access Swanswell peer mentor groups also attend a separate organisation called SMART Recovery¹. The programme works by helping participants to decide whether they have a problem, building up their motivation to change and offering a set of proven tools and techniques to support their recovery. Many of the Swanswell service users commented that the sessions run by SMART are very helpful.
- Several service users commented that having regular contact or having the potential to increase contact with family members and children would motivate them to stay on the path of recovery.
- Having a named person that understands what service users have been through and their personal challenges would help to keep them on the right track. A Social Inclusion Worker/ Key Worker is a positive link in the recovery of some service users.
- We were told that recollecting the trouble that alcohol has caused in their lives and the fear of going back to a bad physical and emotional space could at times be enough to motivate them to stay well.
- Service users told us that attending groups and meetings and knowing that each week service users will meet peers motivated them on their recovery path.
- Being kept busy through volunteering or paid work often made users feel part of the real world and also motivated them.

#### **Question 3:**

80% of respondents told us that additional support would be helpful. Service users told us that being able to access other forms of support in one service, such as mental health, employment and housing, would be beneficial. Also, because they had built a relationship with Swanswell, it would ensure a seamless process if all of these were provided in one place.

28 Mental health

15 Housing assistance

Employment

**E** 14 Financial help/advice

10 service users told us, that there was nothing else needed to support the recovery and 2 service users responded saying there was something else that could support their recovery.

<sup>1</sup> SMART Recovery (Self Management and Recovery Training) is a science-based programme to help people manage their recovery from any type of addictive behaviour.



### What Staff members told us

### Improvements from within

We wanted to look at the service overall and recognised that staff are well placed to identify areas of improvements to services. We asked staff what, if any, changes to the service would better support them in the course of their work and would allow them to give better care to service users.

We invited suggestions for improvements and were overwhelmed with the range and number of responses received. We collated the suggestions and ideas under headings and summarised the feedback.

This is what emerged from staff experiences:

#### **Training**

Improving training for front line staff within A&E departments, Out Of Hours GP's and acute medical care. Workers could also be trained in specialist areas for example, pregnancy and novel psychoactive substances sometimes known as 'legal highs'.

#### Welfare

- Staff felt that caseloads had increased significantly over the past few years. It was mentioned that large caseloads might reduce support offered to individuals within the service especially with the other duties expected of staff when in the office.
- Improving practical working solutions, such as staff being able to work from home or having access to new technologies i.e. tablets, would allow paperwork to be completed immediately and help reduce duplication of work.
- Staff mentioned that they would like to see improved support for staff members to perform their duties, for example, opportunities to debrief, discuss expectations of workloads and the ability to prioritise clients.

"Service users should not be limited to cross border services. The City and County services and resources could be aligned to offer greater access and capacity"

- Swanswell staff member

## 9

### Operations and new ways of working

- A greater staff presence within Leicestershire and Rutland would make it easier to facilitate changes within referral levels and staffing. A review of the geographical placement of staff in order to reduce travel between external working hubs and maximise time spent with clients.
- Returning to hubs/offices following an appointment may not always be feasible or the optimum use of time. Better Internet connectivity in outreach offices and drop-in premises would enable more effective working.
- It is often difficult for staff to find viable options for service users to take part in a structured session or activity due to varying numbers. Having enough people to make topical sessions worthwhile and feasible can be challenging. For example, mutual aid groups, hobby-based activities such as art groups, crafts and sports can promote wellbeing and give structure to people's lives.

- Staff suggested that finding ways to streamline the assessment paperwork would be helpful as a lot of time is spent completing forms that could be spent with service users. Reduction in the amount of duplicate paperwork, particularly on certain internal systems, was of particular concern.
- Risk assessments and care plans should be shared between Substance Misuse Workers and Recovery Workers on the computer system to increase information sharing and reduce duplication. Currently, when an assessment is completed, staff felt that effectively, they fill out a risk assessment twice: once in the assessment and once separately. There is a question as to whether there is a need for both.
- An option to deliver group interventions and not just one to one interventions may benefit the service users and would allow staff to use their time effectively.

"Communication is key when dealing with patients with addictions, particularly given the complexities of their mental and physical ill health"

- Swanswell staff member



### Improvements from within

### Partnership working across sectors

- We were told that it is a common occurrence for the pharmacies that work with Swanswell to call in to the office stating that they are missing prescriptions. This in turn causes a knock on effect on work for all concerned. Staff stated that having a specific member of the team who could check any problems with prescriptions would be very helpful and reduce the chance of a service user going without their prescription.
- We were told that when service users are admitted to hospital under emergency circumstances, at times, communication could be lacking. Staff had known of occasions when procedures were not being followed by emergency staff. This meant that there had been times when prescription checks to confirm that a patient was in receipt of a controlled drug, had not been made. Also there were times when the service user's treatment worker was not advised of admission or discharge,. Both of these circumstances have serious implications for the service user.
- Set up a one-stop shop so that external services such as mental health workers can come into the premises once a week to see any service users that need referring to them. The same could be done with the job centre, areas such as sexual health and other services to improve access.
- Explore an option of a daily drop-in that assesses new service users and supports referrals with a scheduled time. Often clients will drop-in when it is convenient for them and making this first step can be difficult.
- Staff in both commissioned and statutory services could work efficiently together when supporting individuals if there were better understanding of confidentiality and information sharing agreements across services.

- Improvement in accessing mental health services for service users. If mental health professionals were assigned to the commissioned service, specifically for service users, this would deliver better care to service users and support staff to work with their clients.
- Joint service delivery between the City and County services enabling pooled resources with one central holistic focus on services.
- Better use and partnership working with community pharmacies (that provide a range of health services, some funded by the NHS and some by local authorities), for example: Blood Born Virus test and vaccination, Nurse Medical Prescriber for shared care, alcohol brief interventions, Naloxone distribution, level 3 needle and syringe programme.

#### Young people

- Having specialist workers would be of benefit, such as a Hidden Harm Worker, Diversionary Activities Worker, and a University Liaison Officer would be helpful. Dedicated workshops around novel psychoactive substances (legal highs) and steroids and image enhancing drugs may also be an area to better understand.
- Diversionary activities, a group worker helping with access to services, activities and courses that young service users could progress with whilst on their road to recovery, would all be of benefit.





## Healthwatch Insights: Conclusion

As a local health watchdog, it is important to bring as many voices to the forefront of commissioner conversations as possible. This report highlights issues that remain important from a service user and staff perspective and provides a greater understanding of their experiences.

#### **Empathy and holistic approach**

Service users prize empathy highly in how they view the care that they receive. Therefore a greater understanding of their everyday struggle on the path to recovery by workers and professionals is encouraged. Their plea is to be supported emotionally, physically and mentally by those providing medical treatment.

#### Tackling stigma

Addressing the stigma service users feel and experience is another area that should be addressed by the public. There needs to be greater understanding that drug and alcohol misuse is a period of illness affecting the body and mind. A campaign to detract from the stigma service users feel and experience should be considered.

#### Listening to staff

Providing frontline staff with regular opportunities to drive and improve service delivery is important and should be encouraged for continuous development. Listening to the individuals that perform the day-to-day tasks can often be very insightful and beneficial to the organisation.

#### Listening to service users

Based on what service users told us, there is a need to better understand the different approaches that could be taken to enhance their recovery and to review when and how support is delivered. This in turn may inform outcomes against which commissioners procure services.

Healthwatch Leicestershire will continue to gather evidence and insights from service users and the public to champion their voice at every opportunity.



### What comes next?

## What Healthwatch Leicestershire will do with the data collected

We will submit this report and findings to

- The Leicestershire County Council commissioners and Swanswell
- The Leicestershire County Council Health and Wellbeing Board
- The sub-regional Substance Misuse Clinical Forum for Leicester, Leicestershire and Rutland, hosted by Leicestershire County Council.
- The report will also feed into the Substance Misuse Review/Procurement process of Leicestershire County Council.





## Acknowledgements

We would like to acknowledge the support and co-operation of Swanswell for allowing us access to their staff and service users.

We want to thank the service users who gave us their time and shared their personal experiences without whom this report would not be possible.

We also appreciate the feedback and comments from staff at Swanswell who aim to improve support for substance misuse services. We thank them for sharing their views on service improvements with such candor.

### How to access Swanswell's services

Anyone who wants help can simply pick up the phone and call Swanswell on 0300 303 5000. A team member will discuss your situation with you and take a referral. Or simply visit our website and download a referral form.

For more information on how to access Swanswell services call 0300 303 5000 or visit our website WWW.SWanswell.org

### Drug and alcohol services in local GP Practices

Swanswell work in locations across the region including community venues and GP practices. In Leicestershire and Rutland Swanswell support GPs to provide drug and alcohol services to their patients. This support is available in 23 practices across the county.

Where possible, service users are seen at their own GP Practice where a Swanswell worker provides a range of interventions to help service users change their drug and alcohol use. If someone has more specialist needs, they are seen by Swanswell's specialist services. These are in two main hubs and across Leicestershire and Rutland.



# Road to Recovery

Voices from Substance misuse service users and staff at Swanswell

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