



Cheshire & Warrington

Infrastructure Partnership

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VS6

COMMUNITY VOICES REPORT: SYSTEM P COMPLEX LIVES COHORT

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Community Voices Report: System P Complex Lives Cohort

This report details and summarises first-hand accounts and experiences of people's voices collected from specific communities across Cheshire & Merseyside.

This forms part of a wider programme of work to better understand the experiences of the VCFSE supporting people with complex lives, through the creation of Community of Practice at Place. The programme aims to enhance partner relationships and create opportunities for coproduction to help address health inequalities across communities, making recommendations for future working to provide better patient outcomes.

The voices, experiences and recommendations detailed within this report are to be shared across the health and care system, feeding into the C&M overarching Complex Lives programme which brings together all 9 places to share best practice, learning, tools, materials, expertise etc. Linking into the Population Health Board, Data in Action board and informing the Public and Patient Involvement and Engagement group. This partnership approach to addressing barriers will provide learning and good practice to better support the Complex Lives Cohort, to influence the design of services and to ensure that our most vulnerable and marginalised communities are put at the very heart of strategy and service development

Co-production & Engagement Fund

The System P programme invested £18k to support activities to enhance Place and C&M understanding of the Complex Lives cohort. The fund was divided between each of the 9 Places equally (£2k per Place). Led by the CVS in each Place (although in some areas delivered via wider VCFSE partners), specific communities were identified and chosen via local intelligence to focus on people from backgrounds and demographics most marginalised and exposed to the cohort.

In total, 120 people were interviewed using a variety of methods including face to face interviews, telephone interviews and group sessions.

Different themes and sub-segments of the population were explored in different Places in order to provide a much deeper and broader understanding of the issues. These have been merged and collated into this overall C&M report. All responses shared in this report are anonymous. The need for anonymity was essential in order to ensure participants felt comfortable providing honest responses.

Placed-based CVS and VCFSE partners were key to achieving the collection of voices in these cohorts, given their closeness to individuals and groups already working with these cohorts and the trust the VCFSE sector has with these communities, making engagement with “harder to reach” communities achievable.

The Questionnaire

Each Place undertook questionnaires with individuals, parents or guardians. To aid the collection of voices and to ensure consistency of approach across each place, a proforma was developed to guide interviews with participants. The suggested questions within the proforma were designed to be flexible and as conversation prompt to ensure that participants could talk freely about their experiences affecting their interaction with health and wider statutory services.

The 5 questions asked to all respondents were:

1. Could you tell us about your experience of using services, both positive and negative? What is the main reason for saying this?
2. What would you say has been a barrier to you accessing services? If you could explain in some detail that would be helpful.
3. Were there other services or support that might have helped you or you would have appreciated had they been available or accessible?
4. Has there been anything that has made life harder or has upset you because of your circumstances and access to health services. What have you found difficult and why?
5. What one thing would you like to change to make services more accessible for people with complex lives?

Partners carrying out the questionnaires

- Citizens Advice Domestic Violence Service - Warrington
- Mixed cohort - One Knowsley
- Drug and substance misuse- Halton & St Helens CVA
- Mixed cohort - Sefton CVS
- Motherwell – Cheshire East
- Hope4More – Cheshire East
- Survive - Cheshire East
- YMCA/SHARE -Cheshire West
- Tomorrow's Women– Cheshire West
- Irish Community Care- Cheshire West



Respondent Cohorts:

- People living in the most deprived areas as measured by the Indices of Multiple Deprivation
- Families with complex lives, specifically with children with neurodevelopment disorders
- Mental health issues alongside physical health issues
- Substance misuse
- High use of emergency care,
- Those who have experienced domestic abuse or the criminal justice system.



It's clear that the cohorts are not a significant enough sample to apply to all individuals across the region that fall into that cohort. Rather they represent a snapshot of experiences from those interviewed with some common themes.

The voices collected are extremely insightful into the lives of those most vulnerable. They highlight frustration, despair and lack of trust and yet in other cases, positivity and the willing to support the system and absolute gratitude for levels of support when accessed at various stages and interventions.

The respondents include a number of people having been in the system for long periods of time, with one person citing to have been in the system for over 30 years due to mental health issues.

It is evident from the responses that some respondents were in a state of crisis at the point of interview and gave exceptionally negative answers relating to identifiable people or services. This has resulted in interpreting some of the responses with discretion.

Overall, the project amassed experiences and thoughts from individuals who were interviewed, with many common themes and many individual themes raised. Due to the numbers this report has only dealt with the common threads from respondents.

Summary of Key Findings

- Over 60% of respondents stated that communications, including written, verbal and IT created barriers, in particular understanding NHS administration, letters, advice and treatments. Accessing health services and appointments online has proven difficult (according to respondents).
- Over half of respondents stated having feelings of being passed around the healthcare system, that a lack of continuity and never being seen by the same person exasperated their situation.
- The NHS system is complicated to navigate and sometimes 'loses' patients due to poor communication across the system at all levels.
- People in the most need often face the greatest difficulty in finding meaningful help, due to a lack of understanding of services and how to access them.
- Respondents highlighted delays in being treated, which also lead to deterioration during the wait. This included increased anxiety from lack of communication.
- Repetition and looping across the system resulting in long waiting times were a significant issue, also resulting in people feeling abandoned or not heard.

Summary of Key Findings continued.....

- A significant number of respondents cited being reluctant to ask for help or not wanting to waste NHS or other service providers time, many only accessing services at crisis point.
- An identified lack of mental health support, this included support for young people and children in particular with neurodevelopment disorders.
- A lack of treatment options leading to inappropriate (in the view of respondents) or no solution provided.
- A tendency (reported by respondents) to prescribe medication rather than alternative solutions. The findings highlight a lack of treatment for underlying conditions and wider determinates of health issues rather than presenting needs
- Treatments seemed to be short-term solutions or limited to a fixed number of sessions, any step down pathways were not consistent
- There seemed to be a lack of knowledge of the health and care system, both by members of the public, VCFSE and healthcare professionals. This was cited though a number of conversations with poor cross-sector service support.

The Responses a selection from all cohorts & place:

“While I have found services to be good it is sometimes quite hard to get hold of people to speak with them and this can be quite stressful”

“Not knowing exactly what services are out there for me to access was a barrier”.

“I struggle to speak with people over the telephone as I find it hard to discuss my situation and would like there to be more face to face appointments or drop ins for access to services”.

“I was never allowed to see anyone due to my abusive relationship and had always been told that you only speak to family. The only thing that was difficult was that I did not know that there was such a range of services available to me. Once I was made aware of these services and organisations that are out there, especially ones that help women, I found them all very easy to access. I will be making others aware of these services and encouraging them to attend them should they need to”

“One thing I would definitely change would be the way that people receive appointment letters through the online portal. Not everyone is IT literate and having to only receive appointment letters via the online portal but also rearranging them through that is hard”.

“I think that an online request service similar to e-consult or a messaging services used by services such as CAMHS and other mental health services would be helpful for people like myself who sometimes struggle to access services due to having 3 autistic children”.

“I suffer from chronic pain due to trauma and incontinence. Every time I saw a different GP I had to explain my issues again and I felt that it would have been good if they had checked/read my records before they saw me. At one point I was considering killing myself because I could not gain the help that I needed”.

"Passed about and dropped – no joined-up care. Asked GP, for support and assessment for Premenstrual Dysphoric Disorder. Absolutely dismissive, passed off, ignored and feel forgotten.' Misdiagnosed with Bi Polar Disorder by someone unqualified to make a diagnosis. 'Slipped through the net' during a change of computer system at Mental Health services. Told to look at non-NHS forum for support for Premenstrual Dysphoric Disorder symptoms."

“I think that it would be good to have more services available to people in my situation such as an outreach service to provide help with such things as homelessness and care”.

“Making it easier and quicker to receive replies from services as sometimes it is a struggle contacting people and receiving a reply due to annual leave and non working days. This is not a complaint and I understand that people have annual leave and only work on certain days but if I get something in my head that I need to discuss and there is a delay in their response this can make things more stressful”.

"The NHS have six sessions and then you're fixed, mentally"!

"I spoke to my doctors and all they did was give me tablets that made me worse."

"Not listening to me. Only sending me links. Fobbing me off to other services saying it's not their area, and then going round in circles and getting nowhere and back to square one, or they don't get back to you to follow up, whether you leave a voicemail message or email, being ignored is very frustrating."

“Always feel guilty at taking up space. Past experience with NHS mental health services and the Police.”

"To treat each person as individuals. I understand services are under a lot of pressure, but being continually told that I don't meet the criteria is heartbreaking. It makes me not want to carry on."

"I've had people come out at home when I've been suicidal, from the crisis team but they sent two men and this is stressful for me due to previous sexual assault – I now won't call in case I am sent men. I'm very uncomfortable working with men and having them in my home".

"I don't know if I would have gone to a 'service' as such-I think that was my problem with community alcohol services. I never thought my problems were extreme enough and that they were for people with serious issues. The wording can put people off. 'Domestic Violence', 'Alcohol service', 'Crisis Team'. I never really felt worthy of any of these and it seemed I was being labelled or put in a box. I just want to have a normal life and not have to rely on services".

"My experience involves being taken to the hospital some time ago, where the ambulance arrived extremely fast, which is a positive aspect. However, the negative aspect was the extended wait time in the hospital before someone attended to me, which exceeded 7 hours without anyone inquiring if I needed assistance. Additionally, a language barrier existed, particularly for foreigners like myself, causing difficulties in understanding technical medical language".

"Explanation of healthcare services in my own language would have been fabulous"

Recommendations

A series of suggested recommendations have been developed based upon the voices collected, experiences shared and themes identified in this work. Throughout the report one of the most common highlighted experiences raised by the respondents was the feeling of being passed around and telling the same story, alongside a struggle in accessing health service appointments. Also, an identified lack of mental health support, this included support for young people and children in particular those with neurodevelopment disorders. A number of respondents raised feelings of guilt accessing support and ‘services’ alongside not having an understanding of services available to them.

- Patients focused outcomes at the heart of all policy and service design.
- Data sharing agreements across the system
- Accessible communications and services



Communications

There is a clear need to develop ways of ensuring communications are understood, inclusive and wide reaching. The VCFSE is ideally placed to support with communications and engagement across communities, through a wide network of over 19,500 VCFSE organisations across C&M [Cheshire and Merseyside State of the Sector 2023 — VSNW](#)

The VCFSE can play a pivotal role in communicating with groups that are considered “hard to reach”. There are opportunities and examples of good practice across C&M mobilising Health Champions, Good Neighbours, Making Every Contact Count community initiatives and Digital Champions to improve communications and community connections to services. There is also the opportunity to work with the sector to coordinate an imaginative use of media and community-based services targeted at specific cohorts

Connecting Communities

Social prescribing was identified by respondents from across all cohorts as a generally positive experience providing essential and inclusive health and wellbeing support. Being signposted or supported to access services was noted as extremely valuable and is considered a trusted approach to accessing the most appropriate service at the first point of call.

The sector has a strong track record in reaching those who are not only difficult to reach but also difficult to find. The voices gathered in this project have evidenced that, along with social prescribing, the work of the VCFSE sector is invaluable in reducing inequalities and delivering prevention services. However, it should also be recognised that any form of social prescribing requires investment to ensure under resourced VCFSE organisations are able to meet any increase in demand.

VCFSE Equity

Closer working between statutory services and the VCFSE as an equal partner in service design and delivery will allow health services to benefit more from the sector's flexibility, adaptability and community expertise whilst drawing out excellence from the sector itself. More often, the sector is better able to address the wider determinants of a person's health through preventative services that help to reduce the need for health and social care services. The codesign of services to provide step down support through sustainable community-based provision, to support the complex lives cohort would provide a cost saving to the NHS and improved outcomes for patients

By unlocking the capacity of the VCFSE sector in its role within health and care, we can work together to adopt new ways of working that truly reflect and address the needs of communities, tackle health inequalities and create a Cheshire and Merseyside where everyone can prosper.

For further information on the Complex Lives Voices please contact

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