



# Health Inequalities Community Insights Project

Accessing Preventative Health Measures with a focus on:

- Annual health checks for those with learning disabilities
- Physical health checks for those with enduring mental ill health
- Vaccination uptake for those from diverse ethnic minority communities

Report by Community Action Network, Dorset Community Action and Dorset Race Equality Council, May 2022



# Executive Summary

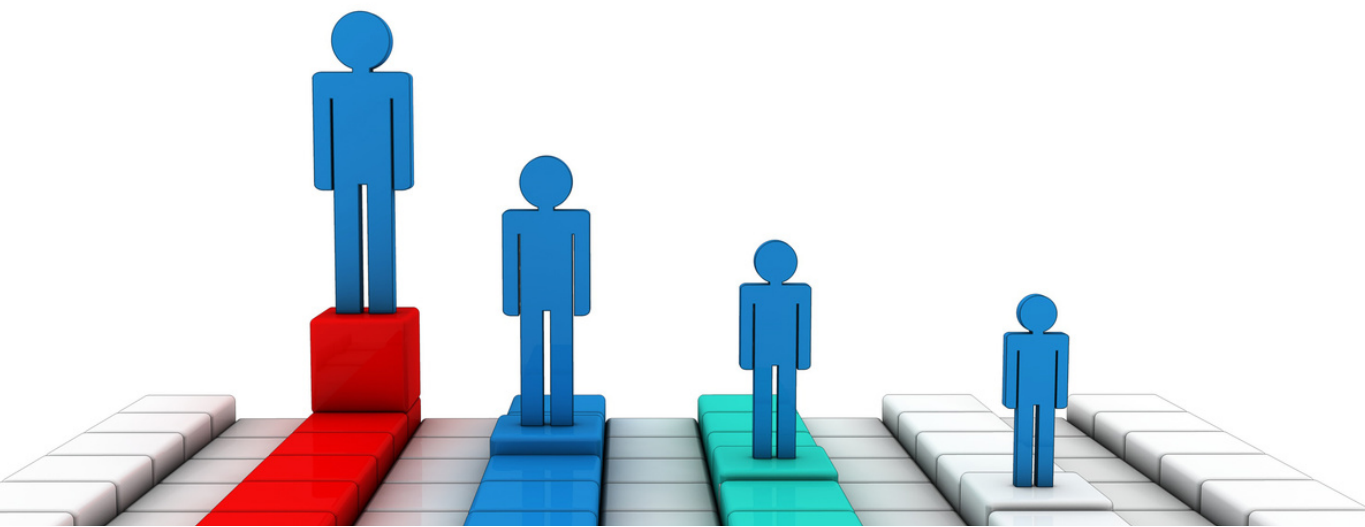
We would like to extend our heartfelt thanks to the people who shared their lived experience with us, and we hope this will inspire and drive positive change. We'd also like to thank the voluntary, community and social enterprise (VCSE) organisations who made this report possible. A full list of all those involved can be found in Appendix 1.

This was an exciting project involving communities and enabling us to explore and gather insight into the areas of hidden inequality that three key communities face and how the VCSE could help to build resilience. The communities are:

- Ethnic minority
- Learning disability
- Enduring mental ill health

Through this research we were particularly interested in identifying why specific communities are reluctant to access preventative healthcare measures such as:

- Annual health checks for those with learning disabilities
- Physical health checks for those with enduring mental ill health
- Vaccination uptake amongst diverse ethnic minority communities.



Although a lot of people we spoke to were happy, there were significant amounts of people who made suggestions and highlighted areas we can all work on. The responses we received were varied and the key themes identified from the insights are:

- Experience with healthcare provision
- Preventative healthcare
- Communication and information
- Support and wellbeing
- Discrimination

The VCSE organisations we engaged with throughout the process were particularly supportive in sharing their ideas on how we can work collaboratively to deliver the recommendations in this report.

We believe implementing the recommendations, some quick wins, other longer term culture changes, will better empower some of the most seldom heard people who struggle to access health care to better access services in a timely manner.



**inequality**

# Introduction

[Community Action Network](#), [Dorset Community Action](#) and [Dorset Race Equality Council](#) (DREC) were commissioned by Public Health Dorset and NHS Dorset Clinical Commissioning Group (CCG), to gather community insights and identify any areas of hidden inequality that people with enduring mental ill health, learning disabilities and ethnic minority communities face and their reluctance to accessing preventative healthcare measures.

Through this report we will be describing how we carried out this research and highlighting some of the key insights from individuals and the VCSE organisations who took part in the focus groups, interviews and survey. We will be rounding up by drawing out some recommendations that the VCSE sector and partners can do together to enable an increase in an uptake of preventative healthcare measures particularly from those within the identified communities.

Having conversations with the local community enabled us to share the identified insights with the NHS, wider social care and voluntary sector to improve and develop services for the people that really need them. Population groups with the greatest inequalities in uptake of preventative health measures identified for inclusion were:

- People with a learning disability accessing annual health checks
- People with an enduring mental illness accessing physical health checks
- People from ethnic minority communities accessing vaccinations

Working collaboratively with our wider VCSE network partners, who specialise in supporting the identified population groups, enabled us to gather insights on why those most at risk do not access preventative health measures such as vaccinations, health checks and appointments. Thus, providing a gateway to participants who are not normally approached to take part in these kinds of projects.

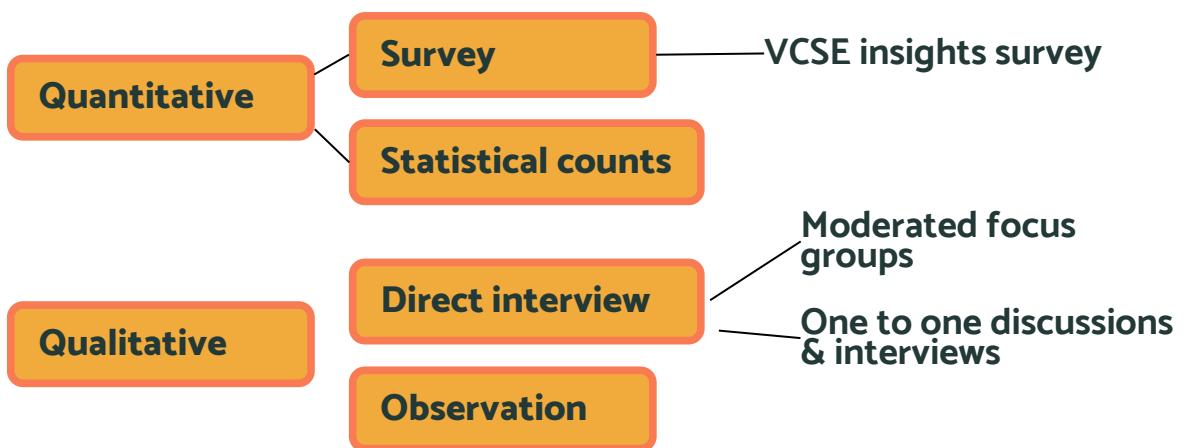
It was agreed that this would be carried out through:

- **focus groups** - participants were identified through analysis of baseline data held on DiiS ensuring those of greatest inequalities were invited to take part.
- **a sector-wide survey** - enabling us to gain a macro level of insight, around wider core issues that our VCSE partners see as barriers and the difficulties they perceive on behalf of their service users in accessing preventative measures. Through this VCSE partners were invited to suggest potential solutions that they can offer to these barriers.

DREC's methodology was different: They carried out individual interviews with specific ethnic minority categories identified as having a low uptake of the Covid-19 vaccinations according to information held by NHS Dorset and conducted a survey targeting individual respondents from those communities. The main ethnic minority categories were:

- Black African
- Bulgarian
- Chinese
- Indian
- Polish
- Romanian

# Data collection techniques



The project allowed us, through a grant-making pot, to support and involve our vital VCSE partners in the project, allowing for the work to take place at greater speed and with minimum disruption to their day-to-day business as additional capacity to enable involvement was funded.

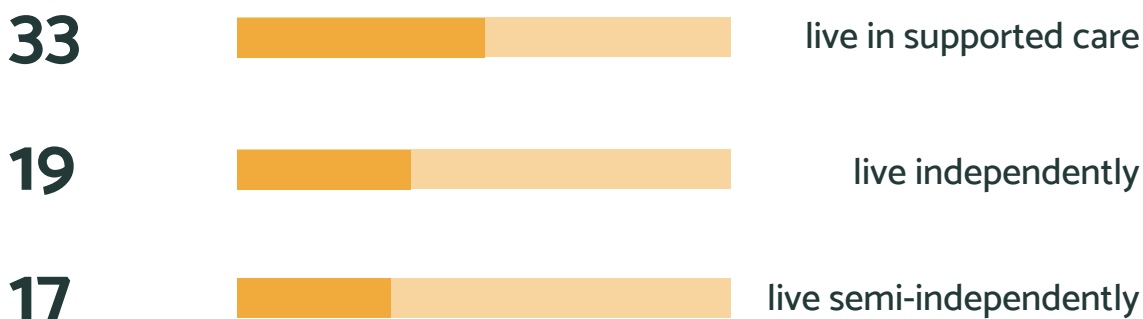
The agreed project outcomes were:

- An increased understanding of health inequalities across a local area
- Clarity on why flu jab uptake is lower in our most deprived areas
- Co-production of recommendations to create a sustainable change around the uptake of preventative programmes to reduce health inequalities in Dorset
- Actions completed that were achievable from the co-produced recommendations from the project
- A baseline position to monitor key health data and those communities and groups from which to assess the increase in uptake of preventative programmes are established utilising Diis
- A range of insights gathered, analysed and used to inform preventative programme planning – using the uptake as an indication of the success of the project
- ICS partners engaged to develop broader community data and insight
- Data collection will be used to inform the flu/Covid-19 vaccination programme to increase uptake in the identified population groups

# Demographics

Working together with our key VCSE partners we aimed to invite a mix of male and female participants from a wide age range who were 18 years old and over. A full breakdown of the age, gender and geographical area for each cohort is available in appendix 2.

We had conversations with 69 individuals with learning disabilities. Of those:



We engaged with 58 participants with enduring mental ill health. Of those, approximately 20 have a severe mental illness (SMI) diagnosis.

We interviewed 4 SMI Physical Health Check Social Workers and had conversations with various Health Professionals (GPs, Nurse Practitioners and Support Workers).

We engaged with 87 people from selected ethnic minority communities. These were from Black African, Bulgarian, Chinese, Indian, Polish and Romanian ethnic groups. 12 individuals did not disclose their ethnicity.

- 47 completed the online survey
- 28 attended one-to-one interviews
- 12 attended focus groups

# VCSE Sector Survey

An important area of our research was to capture the voluntary and community sector's perspective and identify any areas of hidden inequality that their services users face and to find out what support they can offer to improve access to preventative healthcare in the community.

We invited key VCSE organisations across Dorset to take part in our health inequalities insights survey to share their experience, perspectives, advice and passion with us.

From all those invited, we received **43 individual responses** from **35 different VCSE organisations**. A full list of organisations is available in appendix 2.

The survey responses have provided valuable insights and identified that there is a wealth of support and services available in the VCS and organisations are keen to be involved.





A few examples of the questions we asked the voluntary sector:

**“What activities do you carry out that directly or indirectly improve the physical and mental wellbeing of those you work with?”**

- Wellness group, friendship clubs, walk and talk, speaking up groups (People First Dorset)
- Counselling, 1-1 psychoeducational support, eating disorder service, peer support groups (Dorset Mind)
- Drop in housing and benefit advice. one to one support work. Homelessness prevention (Lantern Trust)
- Group workshops: arts & craft sessions (tie dying; modelling with polymer clay; cooking (BCHA)

**“What difficulties and barriers to healthcare do you think your service users face?”**

- Rural location, lack of services locally, main hospitals an hour away at least, lack of public transport, long waiting lists for primary mental health services (Mental Health North Dorset Help and Peer Support)
- Health services are not always using reasonable adjustments to support the person with learning disabilities eg. easy read information, longer appointments (People First Forum)
- Access to GPs, not getting annual health checks, hospital appointments, people being treated as individuals (Diverse Abilities)



## “What support could your service offer to improve access to healthcare provision?”

- 1-to-1 support, guidance and help in managing challenging mental health episodes. (One Big Scribble)
- Peer support, expert advice and guidance, advocacy, holding services to account (LGBT+ Voices Dorset Forum and Dorset Disability Equality Forum)
- We can provide access to a treatment/consultation room for any healthcare provider that supports veterans (The Veterans Hub Weymouth & Portland CIC)

Participants were particularly interested in tackling the wider issues highlighted in the research and the subsequent recommendations. Many requested to be kept informed of the next steps from the report and an opportunity to be part of the action plan helping to create sustainable change in Dorset.



Full details on the survey can be found in appendix 4.

# Insights

During the focus groups, interviews, and fieldwork, we had conversations with participants asking various open-ended questions about their experiences accessing healthcare, what support they have or what would make it better.

Overall, the insights we received were generally positive with many people happy with the healthcare they receive and the support that is offered to them across Dorset. However, there was a significant input from people, particularly those from ethnic minority communities, that felt less than happy with the healthcare they experienced, and their insights give us some useful information about where recommendations for improvement can be made.

The responses received were varied and themes identified from the insights are:

- Experience with healthcare provision
- Preventative healthcare
- Communication and information
- Support and wellbeing
- Discrimination



# Learning Disability Insights



## **Experience with healthcare provision: inaccessibility of appointments**

Participants with learning disabilities told us they are sometimes directed to use the online GP E-consult form, which is a barrier. It is not in easy read format and does not meet everyone's needs or abilities.

"The GP online form is very difficult for me to use. I don't like it and I have no other option. It is also not in easy read which helps me."

- Macy, Aged 50

You can also read about Sharon sharing her experience as a carer and the challenges she faces when accessing healthcare for her daughter, Katie who has Down Syndrome in appendix 5.

## **Preventative healthcare: services offered in an inaccessible way**

We found some individuals with learning disabilities, from their perspective, have not been offered their annual health check since 2019. Some have been offered a "telephone health check" but have said they are less effective and not preferred, they would like face to face health checks as standard which gives them more reassurance.

Through the survey VCSE groups told us that individuals find it difficult to attend GP practices and health settings as it can be overwhelming and often avoid unless they feel it is necessary.

## **Communication and information: understanding individuals' needs**

Many of the participants we spoke to have experienced challenges when accessing healthcare (including preventative) services, particularly when booking appointments often facing communication barriers with frontline staff.

“I find it very hard to get an appointment when I call. I feel like I’m bothering them (the receptionists) [...] Once you get to your doctor it’s fine, getting to them is a nightmare” - Jack, aged 20

Individuals are encouraged to be independent or do not have full-time carers. Consequently, they often attempt to contact their GP surgery independently often unsuccessfully due to communication barriers. This results in reluctance to engage in the future.

## **Support and wellbeing**

Participants said more specialised mental health support for those with learning disabilities is needed, especially relating to their health concerns and the Covid-19 pandemic.

## **Discrimination**

We found that individuals with learning disabilities who live more independently are deemed at higher risk of facing discrimination, not accessing all preventative services or do not regularly participate in wellbeing activities compared to those with more support.

“... when they speak to me like I am a 3 year old, like I don’t understand English, or they speak to my mum asking her to answer for me – I don’t like that. I am an intelligent person with learning disabilities. That doesn’t make sense to them. Some get this, though...” - Jenny, aged 25

# Enduring Mental Ill Health Insights



## Experience with healthcare provision: barriers

The participants we spoke to with enduring mental ill health said they regularly experience various barriers when accessing healthcare services, including communication barriers, lack of support, difficulty accessing services and services not meeting their needs.

“We urgently need to design and implement trauma-informed top to bottom NHS services, tailored to meet the psychological needs of patients who might have a history of being abused.” - Michael Taylor, GP, Ideas Alliance CIC

Read about the challenges Starfire faced after he had a psychotic episode following a change in medication when accessing healthcare in appendix 6.

## Preventative healthcare: diagnostic overshadowing

“My physical illness and ailments are not taken seriously when I tell them, I am made to feel like I am wasting their time” - Seth, aged 20

Some participants feel their physical health issues are not always taken seriously; their concerns are often directed to their mental health being the cause (diagnostic overshadowing). They said this leaves them feeling frustrated and put off accessing their physical health checks and health services in the future when they have concerns.

“I feel some doctors are quick to diagnose without listening further or looking into my issue properly” Kerry, aged 25

## Communication and information: lack of clarity

Many participants felt a lack of clarity with their mental health diagnosis, either feeling “too quickly diagnosed” or not understanding their overlapping symptoms, leading to a difficulty in finding the right pathway to receive help or therapy.

## Support and wellbeing: inaccessible crisis support

Many participants have said the CMHT crisis number (the Connection Service, via 111) does not meet their needs especially in a moment of crisis, some advised they had waited up to 40mins for support which can then result in their crisis escalating while waiting.

“They keep on sending you back and forth between Steps 2 Wellbeing and CMHT, as you’re either too unwell for Steps 2 Wellbeing or not ill enough for CMHT. There’s no halfway house even if most people with mental illness are in the grey area most of the time.” - Sarah, aged 56

Many participants we spoke said there is a lack of support while waiting to receive talking therapies (eg. Steps2Wellbeing and CBT)

## Discrimination

“There is a generalised picture of what mental illness looks like: erratic, impulsive, aggressive, physically restless - and if you don’t fit in it, they don’t believe you suffer from mental illness.” - Dorian, aged 41



# Ethnic Minority Community Insights



## Experience with healthcare provision

Participants shared their experience of healthcare in their homeland being very different to their experience in England, resulting in feeling dissatisfied with what they consider to be dismissive attitudes from GPs/NHS staff and a failure to provide treatment. Consequently, those who can pay privately or travel abroad for treatment do.

“As a Polish person, I come from a country where we over-medicalise things. When you go to the doctor you expect lots of drugs and lots of tests and lots of speciality doctors to be involved. Here things are different - doctors are not keen to prescribe lots of medication but I know lots of Polish people who feel neglected because they expect heavy duty medicine.” - Interviewee

## Experience with healthcare provision: lack of translators

Interpreters are often not available or fully competent and this is impacting on people’s ability to access healthcare. It was highlighted that people would also benefit from more translated information.

“9 times out of 10 the interpreter doesn’t arrive for my medical appointment, and this has hindered diagnosis.”

- Participant at focus group





## Preventative healthcare

We engaged with 28 people who were not vaccinated against Covid-19 and a further 3 interviewees who are vaccinated despite significant concerns. Two people from the focus group said they will not go back for a booster jab. Some of their concerns were that they were unsure about the long-term health impacts, safety with medications and a feeling that it is an “experimental vaccine”. Read Pavel’s insights into why he has decided not to have the Covid-19 vaccine in appendix 7.

## Communication and information

Some participants we spoke with felt appointments were difficult to access with receptionists acting as ‘gate-keepers’.

“Every time I need to see a GP, there’s only phone consult available and even that isn’t given because reception staff take it upon themselves to assess if your health requires it.” - Survey respondent

Other participants felt that appointments they have had with health professional were rushed and with little empathy or understanding that English was their second language.

“A few times, I felt like the treatment has been given to me with little sympathy, coldness, no engagement and humanity as English was not my first language.” - Survey respondent

## Discrimination

It was felt that there are issues around under-representation of minority communities within the healthcare sector. Some felt that there is a need for greater understanding of varying cultural expectations around healthcare. Shona shared her opinion as a black woman about the healthcare in Dorset and how she can feel stereotyped in appendix 8.

# Recommendations

The primary aim of this project was to gather community insights and identify any areas of hidden inequality that people with enduring mental ill health, learning disabilities and ethnic minority communities face. These groups frequently have more negative health outcomes than the general population of Dorset.

The second aim of the project was then to look at how the VCSE sector could support health care services to overcome these barriers and to enable greater equality of service provision.

Through this project several key recommendations have been established, co-produced as a combination of the field work carried out with individuals and the expert opinion from VCSE organisations that took part.



# Learning Disability Recommendations



When talking to individuals they told us that they found it difficult to access healthcare and have had difficult experiences when they have putting them off accessing services in future.

There is a need to look at how the VCSE sector can offer more support and potentially advocate for those who live independently with learning disabilities, to ensure they are well supported and have a voice when accessing healthcare services.

These recommendations have been developed following the discussions with participants and VCSE organisations who have taken part in the survey, focus groups and interviews.

## **Experience with healthcare provision:**

Research suggested that often individuals with learning disabilities do not feel confident in accessing healthcare and have had poor experiences in the past which have put them off accessing health services in future.

Participating VCSE organisations have highlighted the need for peer-led development of training for individuals with learning disabilities on planning for appointments, self-management and how to access support with the support of VCSE organisations and PCNs.



## **Preventative healthcare: services offered in an inaccessible way**

Individuals and VCSE organisations told us that they felt preventative healthcare has not been offered in a way that is accessible to them.

VCSE organisations suggested better integration of primary care, secondary care and the voluntary sector for collaboration, information sharing and delivering services, e.g. voluntary sector used as outreach points for clinicians to deliver services (annual health checks/screenings).

## **Communication and information: understanding of individual needs**

A common theme throughout was communication and difficulties participants had in understanding and being understood.

Recommendations to address this include:

- The co-development of ‘champions’ (health colleagues) and volunteer buddies specially trained by VCSE organisations who can act as supporters within health settings
- Replication of the current successful Covid-19 Trusted Voices project that has been taking place in collaboration with Public Health Dorset, CAN and DCA to enable individuals with learning disabilities to become Trusted Voices within their communities, creating an effective two-way communication channel
- The development of a short videos to help manage health conditions, treatment and prevention, created in partnership with the community, PCNs and VCSE organisations
- VCSE organisations providing support in writing easy read materials to help individuals with learning disabilities understand information
- Regular peer-led health and wellbeing focus groups to enable those participants who enjoyed sharing their lived experience through this work to continue to be involved

## Support and wellbeing

The research identified that there is a need for a specialised mental health support initiative for individuals with learning disabilities in collaboration with specialist VCSE organisations (such as People First Dorset and Dorset Mind working together).

This would address the concerns raised by participants that there was a need for mental health support for those with learning disabilities relating to their health concerns.

Our research found that elements of this work is being carried out by different VCSE organisations or GP practices. However, it is very limited and is uncoordinated which means those who are not engaged with support services will be missing out.



# Enduring Mental Ill Health Recommendations



When talking to participants with enduring mental ill health and the VCSE organisations who support them, the comments made echoed many of those difficulties that individuals with learning disabilities faced, such as finding it difficult to access healthcare and once having had a difficult experience, being put off accessing services in the future.

As we highlighted previously there is a need to look at how the VCSE sector can offer more support and potentially advocate for those who live with an enduring mental illness, to ensure they are well supported and have a voice when accessing healthcare services.

These recommendations have been developed following the discussions with participants and VCSE organisations who have taken part in the survey, focus groups and interviews.

## **Experience with healthcare provision: barriers**

Participants highlighted that they faced a plethora of barriers when accessing healthcare services which often revolved around the difficulties of being in a formal healthcare setting or somewhere they were unfamiliar with.

The VCSE organisations involved in the project felt that better integration of primary care, secondary care and the voluntary sector for collaboration, information sharing and delivering services would help to overcome some of these barriers, e.g. Voluntary sector used as outreach points for clinicians to deliver services (annual health checks/screenings).

## **Communication and information: lack of clarity**

Participants explained that they often felt they did not understand their mental health diagnosis completely, the impact of the symptoms and difficulty in finding the right pathway for treatment.

There is a need for the co-development of information on various personality disorders/diagnoses and all available treatments on offer which is easily accessible and understandable. This could be done in collaboration with the VCS, healthcare professionals and individuals with lived experience.

## **Communication and information: training**

Participants with mental ill health and the people who support them have suggested setting up an 'awareness and communication training' campaign, involving individuals with lived experience, VCSE groups and PCNs to ensure that healthcare staff are aware of their needs, particularly those who are the first point of contact within health settings.

They have often hit barriers at this first point of contact and feel they need to better understand their needs and the challenges they face, ensuring they are better supported when accessing health services.

Participants enjoyed sharing their lived experience and suggested more regular health and wellbeing focus groups should take place and these could collaborate with existing wellbeing groups run by organisations such as Dorset Mind and Dorset Mental Health Forum. This would provide further opportunities for healthcare professionals to hear about some of the difficulties individuals face and discuss how barriers can be addressed.

## **Preventative healthcare measures**

When we talked to participants about preventative healthcare measures, they strongly recommend using people with lived experience and experts in the voluntary sector to cascade information, provide support and encourage individuals to access preventive services and to lead health related focus groups in the community. Replication of the current successful Covid-19 Trusted Voices project would be an effective way to address this need and enable two-way communication.

## **Support and wellbeing: inaccessible crisis support**

Many participants throughout the research highlighted that support (particularly crisis support) did not meet their needs and they often saw their needs escalate during this period.

It was strongly recommended a CMHT “Live Chat” Crisis Service to be available online alongside the Connection phone line giving individuals instant support in a crisis which they believe would save lives.

VCSE organisations also suggested that primary care and secondary care should work with specialist mental health organisations in the voluntary sector to support individuals while waiting for talking therapies. As an example, One Big Scribble said they are able to offer mental health support to “wait better”. As previously highlighted, our research found that elements of this work are being carried out by different VCSE organisations or GP practices. However, it is very limited and is uncoordinated.

In addition to this we would be keen to explore the opportunities around further developing the Mental Health Alliance to ensure service users with lived experience can inform the strategy.



# Ethnic Minority Community Recommendations



## **Experience with healthcare provision**

Participants' experience of healthcare in their homeland is very different to their experience in England resulting in feeling dissatisfied with what they consider dismissive attitudes to providing treatment.

There is an opportunity to address this by considering working with VCSE organisations to support staff to better understand the experiences of ethnic minorities, their expectations of healthcare provision from experiences of their homeland and the issues faced by people from different ethnic backgrounds. This could include working with different ethnic groups from across Dorset to deliver a cultural awareness training session for PCN staff.

## **Experience with healthcare provision: lack of translators**

Participants shared the difficulties they face in accessing translators or translated information. To address this PCNs could consider working with Bournemouth Interpreter Group to explore the opportunity to commission them to provide interpreters on a regular basis when needed.

## **Preventative healthcare**

Participants who were unvaccinated shared that they were still unclear about the side effects and impact of the Covid-19 vaccination.

Participants wanted to see health information and support offered through peer-to-peer initiatives, working with existing community activity and through trusted individuals within communities.

This could be done by continuing the work with DREC, CAN and DCA working closely with CCG and Public Health through the BAME Community Health Ambassadors and Trusted Voices to develop more translated information about health issues, develop more resources explaining the British health system to the various ethnic community groups within Dorset and share key public health messaging.

### **Communication and information**

It is clear from participants' responses that some of the difficulties impacting on them accessing healthcare services is their understanding of the British health system. Co-designing more resources explaining the system to the various ethnic community groups within Dorset would help address this. VCSE organisations could also work more closely with PCNs to help staff fully understand the ethnic makeup of Dorset and the issues and concerns faced by people from different ethnic backgrounds.

### **Discrimination**

Participants felt that appointments with health professionals were rushed and with little empathy or understanding that English was their second language. VCSE organisations have offered PCN/NHS staff the opportunity to receive action learning session on unconscious bias and becoming more inclusive.

There were several recommendations that were identified through the conversations we had with people from different ethnic minority communities. Consequently, DREC will be writing a dedicated Ethnic Minority Insights report highlighting these additional recommendations.

# Further Insights



There were some clear recurrent themes that were raised when talking to all three of the population cohorts. These included the need for:

- Consistency – ensuring all patients are seen and supported by the same GP/healthcare professional whenever possible.
- Follow up – speaking with individuals who have not attended an appointment to ascertain why this is the case and whether there is something that can be put in place to support them (utilising and connecting them to VCSE organisations support available)
- Transport – several individuals from all cohorts highlighted the difficulties they have in physically accessing health settings due to lack of transport. Further work should be carried out with neighbourhood transport schemes to see how they can meet the needs of patients.
- Extended face-to-face appointments by default and an easier way of accessing appointments for those who struggle with the e-consult forms due to learning disabilities or language barriers.
- Research and development for a 'central point of access' connecting all support and services on offer, linking the voluntary sector with primary and secondary healthcare services and providers to improve pathways, patient support and access for all. There is a wealth of support in the VCSE sector which may not be fully accessed by all across Dorset due to lack of connectivity.
- Identifying ways to improve the service and support gap when transitioning from youth to adult mental health support services.
- Exploring ways of connecting PCNs with patients in the community by having trained skilled listeners, support volunteers or community skilled health workers to support individuals to overcome the barriers they face around physical health checks, vaccination uptake and health and wellbeing improvements.

# Conclusion

The purpose of this research was to engage with the selected population groups, who are less likely to have a voice on their health, in an effective and appropriate way so we could identify key findings on health inequalities across Dorset.

We have gathered valuable insights and recommendations from participants and professionals in the sector which gives strength to the need for these to be acted upon in order to make a positive impact on the health and wellbeing of people from these groups.

Based on the analysis of the data we received we can conclude that individuals with enduring mental ill health, learning disabilities and ethnic communities do regularly experience a variety of barriers and health inequalities when accessing healthcare provision. Following on from conversations with VCSE groups it is clear that there are a range of potential recommendations that are currently at different stages of development and there would be clear advantage of further work to develop these into a clear action plan.



# Appendix 1: Participating organisations

- People First Dorset
- People First Forum
- Prama
- Diverse Abilities
- RJVN8
- Volunteer Centre Dorset
- Autism Wessex
- Pramacare
- Local Mencap - Bournemouth Gateway Club
- Dorset Mind
- Dorset Mental Health Forum
- The Lantern Trust
- BCHA
- Rural Mental Health Matters
- Crumbs
- Prince's Trust
- Dorset & Wiltshire Fire and Rescue
- Sedcat
- Caring Canines
- Headway
- Burngate Stone Carving Centre
- The Dorset Dyslexia Association
- Withyou
- Locus Counselling
- Gillingham Foodbank
- Chestnut Nursery/Cherry Tree Nursery
- Dorset Advocacy
- Rethink Mental Illness
- One Big Scribble
- Dorset Disability Equality Forum
- Space Youth Project
- LGBT+ Voices Dorset Forum
- Veterans Hub
- Muntsy's
- Help for Mental Health North Dorset

# Appendix 3: VCSE Sector Survey

The following organisations completed our VCSE Sector Survey:

- RJVN8 Mental Health
- Lantern Trust
- PramaLife
- The Crumbs Project Dorset
- Wiltshire Fire and Rescue Service - Prince's Trust
- Caring Canines
- Headway (Dorset)
- Dorset dyslexia association
- Mencap
- BCHA
- Burngate Stone Carving Centre
- Locus Counselling
- South East Dorset Community Accessible Transport (SEDCAT)
- We Are With You
- Chestnut Nursery
- Gillingham Foodbank
- Community Credit Scheme - Dorset Volunteer Centre
- Dorset Advocacy
- BCP Area Family Carers Representation
- Diverse Abilities
- Carer Support Dorset
- People First Forum
- Muntsy's
- Mental Health North Dorset Help and Peer Support
- Sheltered Work Opportunities Project
- The Veterans Hub Weymouth & Portland CIC
- Dorset Mind
- People First Dorset
- Space Youth Project
- LGBT+ Voices Dorset Forum
- Dorset Disability Equality Forum
- One Big Scribble
- Rethink Mental Illness

## Appendix 5: Sharon's story

Sharon\*, aged 64, carer to daughter Katie\*, aged 25, with Down Syndrome. \*Names have been replaced by pseudonyms.

Sharon, who is the mother and main carer for her daughter Katie, who has been diagnosed with Down Syndrome, has provided her experience as a carer and the challenges she faces when accessing healthcare for her daughter.

Sharon shared her experiences when accessing her local GP surgery. She said that every appointment and hospital visit would vary in terms of service and care - some experiences were brilliant and other occasions were poor due to staff having the lack of training around the needs of her daughter with Down Syndrome.

Sharon said "Once I rang my GP and spoke to the receptionist about a health issue and was told to call 111, I then called 111 and they said we need to talk to the patient, I explained that Katie has Down Syndrome so they may struggle to get a lot sense from her, 111 said surely she is capable of explaining something to me and was persistent to talk to her. There was a clear lack understanding of her needs or her ability from the 111 operator."

[...]

Sharon suggested "I feel there needs to be learning disability awareness training in GPs and hospitals particularly focusing on the learning disability community's abilities and feelings, especially when it comes to blood tests, needles and new situations which can cause anxiety and stress if not handled correctly."

Sharon confirmed that the issues she has shared are not isolated cases and do happen on a regular basis, she feels that certain aspects of healthcare have gone backwards in terms of the barriers that families face when supporting and caring for a person with learning disabilities.

## Appendix 6: Starfire's story

We share Starfire's truth of the events that unfolded when he moved area in Dorset, in his words and from his perspective. We are not making accusations and do not have corroborating information.

Starfire moved from Weymouth to Gillingham in March 2020, the week the lockdown started, to be close to someone he was in a relationship with at the time. He had stopped taking drugs and made a commitment to a new place and a new start.

He registered with a new GP with whom Starfire's medical history was shared by his previous GP. At the first appointment, the new GP took the decision to drastically reduce his current dose of 300mg of anti-psychotic medication (quetiapine) to 50mg a day. Starfire questioned this decision at the time, but his new GP explained: "I'm not allowed to prescribe you that amount of medication because you haven't lived in the area for long enough". It made no sense to him that changing location necessarily meant changing medication, but he accepted the doctor's decision, as he trusted his previous GP and so had a positive experience to rely on.

Starfire continued saying "Then he said I'm not allowed any more of methadone either if I don't turn up there every day to sign in. But I lived in the middle of nowhere, in a caravan, two and a half miles each way...So they took me off methadone as well just like that."

Starfire sadly had a series of psychotic episodes that lasted for about two months, of which he has hardly any recollection. Several VCS organisations and support workers who had known him previously in Weymouth tried to help him during this time. During this time, his relationship broke down, he became aggressive and was responsible for some criminal damage - he smashed up a Land Rover in the caravan park where he was living at the time, in Gillingham. Consequently, he was banned from the caravan park and became homeless.

A VCS organisation collected him from Gillingham and brought him to St Anne's Hospital in Poole. Soon after, the hospital phoned the VCS organisation at 11pm to come and collect him, as he was being discharged.



They managed to persuade the medical staff to keep him in the hospital until 8am when they would be able to collect him safely. The hospital agreed but 7am he was put in a taxi with a plastic bag of medication he was not capable of understanding when and how to take, and sent back to Gillingham, to the caravan park he was banned from.

When they finally found him, he was clearly in a psychotic episode. He had posted his medication to his mother's address - his mother had been dead for some years. Starfire and the VCS organisation felt he should not have been released from St. Anne's in that state.

Starfire was placed for one night in a B&B where the psychotic episodes resumed, and he tried to force his way into other people's rooms. The police were called, and he was dragged face down across a carpark to the police van, in front of his helpless support team and members of the public. By now, Starfire had accumulated several criminal offences reports and was remanded in custody.

While he was in prison, VCS organisations and support workers tried to help with his case. The report of the prison psychiatrist (from St. Anne's Hospital) that said: 'Starfire needs to be dealt with by the criminal justice system.' Therefore, Starfire was taken to a mental health prison unit where his medication was put back up. After his release, two months on, he returned to the VCS organisation, the Bus, in Weymouth, his support team and his old surgery - Royal Crescent Surgery. He is now the Fire Marshal for the Bus and doing well, supported also by the Lantern Trust in Weymouth.

We understand a formal complaint has been submitted.

Starfire's support worker told us "There are things he did that one could have gone to prison for, but I would argue that if he wasn't in a psychotic episode, none of it would have happened. It wasn't like him to do all those things. Not at all. Even in his report from prison, it said: 'the CEO of the Bus has known him for some time - his behaviour is out of character.' (...) Instead of being offered support for their mental illness, they are handed over to the criminal justice system."

## Appendix 7: Pavel's story

Pavel was interviewed and he shared his view on the Covid-19 vaccine.

“The GP doesn't know about my health problems. I don't have a chance to go to GP and talk about it so this is why I don't make it. (...) The government is saying maybe going to work, maybe don't work. If I come to you and want to sell you a car and say maybe going to work, maybe don't work, you're not going to buy it! Show me proof and proper medics and then yes, but not in a carpark with a guy who is being paid £10 an hour! It is about money (...) The GP takes £12.50 for each person vaccinated. (...) Do you know what is a pandemic? Seeing people dying on street is a pandemic. It is a conspiracy. Show me truth! Then I go and make 10 vaccines. (...) You can be killed now if you talk about Covid. I have people at (work) who don't talk to me anymore and I was friends with them (...) It is very sad. (...) There are children who have no clothes to go to school and you are talking about Covid! You know how much money was spent on Covid? Billions! (...) We are not a car made to put some additive in the petrol.”

## Appendix 8: Shona's story

"I don't think I've actually seen a Black GP. (laughs) Even a nurse. (...) I know people who are Black and want to be doctors but one of their fears is (...) I can't work in this environment because the majority are White people and therefore I will feel uncomfortable in every single situation.

Having all of her healthcare provided by White professionals makes Shona feel stereotyped:

"I think the most important thing for your report is that not everyone is the same so stop treating us like we're the same. All the theories about Black people have this and White people have this... that needs to be disregarded. (...) Each person is an individual. (...) If I go to a GP, don't talk to me as Black Shona. I am just Shona. My health has got nothing to do with my skin colour."