




healthwatch
Oxfordshire




We'd like to hear from members of the Albanian community about their experiences of using health and care services

Share your views using this survey:
www.smartsurvey.co.uk/s/Albanianhealthandcare/

Healthwatch Oxfordshire report for the Care Quality Commission Regional Engagement project: seldom heard communities, November 2021.





“We did not complain because we had nowhere to complain, this is the truth and I don’t know how to make a complain ... as far as I know there is no office! To be honest, I want my peace of family, I don’t want to get involved in these!”

“I don’t want to make problems”

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Contents

1. Executive summary	4
2. Background	7
3. What we heard - people's voices.	8
4. Access to NHS services.....	9
5. <u>Communication issues</u>	1
6. <u>Views on using NHS health and social care services</u>	4
7. <u>Wider factors influencing health and wellbeing</u>	18
8. <u>Raising concerns and being heard</u>	2021
9. How better to hear the voice of seldom heard communities?	23
10. Appendices	24

Executive summary

During summer 2021, Healthwatch Oxfordshire supported a community researcher volunteer to reach out to members of the **Albanian community** in Oxfordshire.

This work was part of a regional engagement project by the Care Quality Commission in which they asked local Healthwatch to reflect the voice of seldom heard communities in their area. In particular, the CQC wanted to understand more about people's experiences of NHS health and social care, and about any barriers faced in raising concerns and having their voice heard.

This report is the result of what we heard, from interviews with seven members of the Albanian community, led by community researcher.

Key findings:

- **Views on raising concerns and being heard.**
 - Knowledge of the CQC and other routes to comment or raise concerns about care was non-existent or limited - people told us they did not know where and how to raise concerns and that more information on how to do this was needed.
 - Barriers to raising concerns included fear of repercussion, fear of causing harm to health professionals, reticence and sense of loyalty to U.K.
 - People also told us they were not sure their voice would be heard, or that speaking up would make a difference.
- **How to best hear the voice of seldom heard communities**
 - We heard that people would like more information about how and where to speak out, in their own language, and delivered in accessible and culturally acceptable ways.
 - People said they would like organisations to reach out with information about the NHS, and pathways to engage, both via trusted health professionals e.g. GPs, and by meeting people in their own communities.
 - Experience of working with community researchers was positive. This approach can bring benefits when building trust and reaching seldom heard communities. However, this approach takes time and must be properly resourced and supported.

We also heard about:

- **Access and navigation of NHS services was varied.** Some found the health and care system difficult and confusing to navigate.
 - People needed information and support to access NHS services, particularly if new to the U.K. Language and computer literacy presented additional barriers for some.
 - People spoke of being reliant on family and friends for booking appointments, registering and navigating health care.
 - Expectations of, awareness and understanding of health and care, treatment and diagnosis was influenced by experiences of systems in people's country of origin.

- **Clear communication with and by health services and professionals was key in accessing and navigating support.** Quality of communication influenced people's experience of health and care.
 - Language barriers presented significant challenges, and interpreter support was mixed and not always offered, sometimes leaving people reliant on family and friends to interpret.
 - People's experience of care was affected by the quality of communication with, and information received from, health professionals. Feeling understood, listened to, respected and heard was important to people's sense of safety and satisfaction.
 - Cultural competence on the part of health professionals was seen as important in feeling heard and understood.

- **Experiences of NHS health and social care services were mixed.**
 - We heard about experiences of using services across the NHS. People valued the care and support they received from health professionals and the NHS. Most were satisfied with their care.
 - Less positive experiences included accounts of not feeling listened to or heard, sometimes perceived as influencing diagnosis, care and treatment.
 - Expectations of health professionals were sometimes influenced by experience of treatment and care in country of origin.
 - There was a lack of knowledge about social care, and some stigma expressed about accessing mental health services.

- **Health and wellbeing of respondents is affected by wider determinants.**
 - The Albanian community members told us about wider factors affecting their health and wellbeing.
 - This included insecure housing, employment and immigration difficulties, and experiences of discrimination from those in authority in the wider support system.



Empowering communities to engage with the Care Quality Commission

- Communities need more information and understanding about how to raise concerns or comment about health and care. It needs to be clear that raising one's voice does not impact on the care you will receive or will cause harm.
 - The CQC and health and care system need to work across all health and care services and with trusted health professionals to raise the profile of routes that people can take to raise concerns or complaints about their care.
 - Information needs to be available in accessible, and culturally appropriate ways, including translated materials and access to interpreter services.
- Reaching out to communities
 - Effort needs to be made to reach out and to meet communities where they are, building trust, working through local networks, and in ways and places that develop respect, security and understanding.
- Seldom heard communities need to be supported to involve themselves, in ongoing dialogue, to help develop appropriate ways to have their voice heard, and to support improvements and change to health and care systems.
 - Working through community researchers, or with community champions can be an effective way of reaching and hearing from seldom heard communities but this needs effective resourcing, recognition, flexibility, and time.
- Healthwatch Oxfordshire has developed some experience of participative and community focused approaches to reaching out to hear from seldom heard communities, and in involving communities in this work. We are keen to develop this community researcher model to hear from more seldom heard communities in Oxfordshire and would work in partnership with CQC. Additional funding would be needed to facilitate this important work.

Background

The Care Quality Commission (CQC) is the independent regulator of health and adult social care in England. Their purpose is to make sure health and social care services provide people with safe, effective, high-quality care. They do this through monitoring and inspecting services, but also through listening to the public and acting on what they hear to bring about improvements. They acknowledge that many people from seldom heard communities may not be aware of what they can expect from health and care services - and few have heard of the CQC as a route to express concern.

In 2021, the CQC recruited 7 local Healthwatch groups across the region to undertake engagement with seldom heard groups in their area. Through this, they wanted to gain a greater understanding of their experiences of health and social care, and barriers they faced in having their voice heard. The brief was to create portraits of communities, engaging with a minimum of **five people**.

What we did and how we did it

Healthwatch Oxfordshire responded to this call, building on its own work within Oxfordshire communities. During the summer of 2021, we reached out to **Albanians** living in the county, through supporting and working with a community researcher. This report gives an insight into what we have heard.

We took the following approach to hear from this community:

- **Working with community researchers:** We recruited a volunteer community researcher. They received induction, support and training to be able to reach out to their communities and hear from them, using different methods. They undertook DBS checks, safeguarding training and received regular face to face support throughout the process.
- The Albanian community researcher held seven **semi structured interviews**, by using WhatsApp video, as well as a short online survey (a further 7 respondents). Most interviews were conducted in Albanian. Interviewees (6 women and one man aged between 20 and 60) had been in the U.K. for varying times, some for a decade or more, and others more recent arrivals. Two had refugee status, and others settled status.
- The focus of the outreach was to **hear from people about their experiences of using NHS and social care**, and to understand what barriers, if any they faced, using services. We also inquired about people's awareness and understanding of the Care Quality Commission, and their **views on raising concerns about the quality of their care**.

- The researcher had support from Healthwatch Oxfordshire staff with formulating topic guide for questions. Conversations were recorded with permissions and transcription and the researchers transcribed their own discussions. COVID-19 restrictions, fears and uncertainties impinged on our ability to follow up with additional events, and to carry out face-to-face engagement.

What we heard - people's voices.

This report is the result of the conversations community researchers had with each community. It is written to let people express their views in their own words. Comments have been grouped into themes, highlighting views and experiences of using NHS health and social care services, and on raising concerns. As common themes were raised by each community, responses are grouped together in this way, rather than separately.

What we heard is grouped across five themes:

- **Access to NHS services** - including experience of navigating the system and cultural understanding of services, finding information and booking appointments.
- **Communication with and by health and care services** - including language barriers, use of interpreters and communication during treatment and care.
- **Experience of using NHS health and social care services** - views and experience of NHS care overall, and of specific services, including GPs, hospitals and maternity services.
- **Wider factors influencing health and wellbeing** - including wider determinants of health such as housing, immigration issues, racism and discrimination.
- **Views on raising concerns and being heard** - including barriers and suggestions for engagement.

Story: Woman with children.

My child became seriously ill with ear infection, I ended up in hospital for one week. While I was in hospital I remember a first case of dissatisfaction with the Doctor, who had my child under supervision. He for 3 days straight gave only paracetamol calpol while my child's ear was dripping with infection, yellow juice. The third day the doctor comes and said to me "Your child is well" although they had a fever, which was not going away ... he said "tomorrow you can leave the hospital".

My husband came and he asked for another doctor to check, because he seemed he did not have proper attention to the child. I didn't know the language well and in my words I said "Smell, smell, the ear smell".. and showed him the stains on the pillow ... he said "don't worry, don't worry" and when my husband asked for another doctor the situation worsened, they brought in another doctor... he, the doctor saved the life of my child, he saw the child carefully and said tests should be done immediately, because the infection could have gone to the brain, I remember that night so bad, at midnight they took my child, in a room further away, the tests, it was terrible. I was listening to my child at the time they were doing the examination, and fortunately, they escaped without having a brain infection, continued with the medication for another five days. So the doctor, the first one, he didn't do the right thing, didn't pay attention, my husband was telling him "What doctor are you, if you being the mechanic, you will cause an accident to the person who fixes a car, not be a doctor to deal with people's lives" It was just the first year I came in U.K. I did not even know the language, the thing were made worst because I had just taken my child from hospital ...

Access to NHS services

Participants spoke to us about their experience of accessing and navigating the NHS health and social care system in the U.K. People commented on challenges of navigating the system when new to the U.K, finding information for the services they needed, and understanding how to book appointments.

➤ Arriving in U.K.

Those who were recently settled in U.K. described their experiences of arriving and needing to access healthcare. Some noted that support from family or friends was essential in learning how to access services:

I came to England to join my husband, and he knew everything it was so easy, we went to the GP and filled the forms ... I was so happy with my

doctor, they were very good and understanding, ... easy it was just to write the name and address down ... (Albanian woman, 30's mother)

When I came into Oxford, in fact it was not so difficult, because I came with my husband, I went with (him) to the GP when we made the registration and (he) was the one who spoke in my side, he helped me (Albanian woman, mother, 40's)

➤ **Grappling with a different system**

Albanian interviewees revealed different cultural understanding of health services and health professionals, based in part on experiences of the support they were used to in their country of origin:

Because Albanians were under communism previously, they have problems and issues with services, and NHS ... they understand the NHS is very good, friendly and communicative, In Albania it's not this type of communication (Albanian woman, 30's)

➤ **Booking appointments**

Common to all was discussion about booking appointments to access a GP and for other health care. People spoke of challenges to access including using online systems, language barriers, and COVID-19. Again, some spoke of needing support with booking and often were reliant on friends or family to help them access care.

I. Booking by phone and online

I used to phone the telephone numbers of the GP and even dentist, and then call them and speak to somebody, I feel more comfortable there ... I haven't seen any ways of doing it online ... directions to go and find a suitable time which is important to me, because otherwise you keep going if you do it online, keep going with emails, and takes way too long ... (Albanian man, 40's)

with the physiotherapist no it has not been difficult. I have communicated by telephone and, I got the note from GP, they have told me that to communicate with them ... have been the simple appointment ... and the appointments are postponed because the Covid situation (Albanian woman, mother, 40's)

When it came to booking (online) you have to receive the letter, confirm the appointment, that was done partly online, which went fine, those instructions were very clear all the time (Albanian man, 40's)

I go online and search if I need something specifically from the NHS, so I make sure that they are NHS websites ... I am IT confident so I feel I can do this ... (Albanian man, 40's)

One woman described the way in which language barriers influenced her ability to access her GP:

After learning the language I made (GP booking) online. Because I did not know how to speak before, I needed to go there face to face to do it. Or I went to the next appointment for example, when I met the doctor I told him to make another appointment ... at that time he make it because I told him I do not know how to speak (Albanian woman, 50's)

Language barriers more widely will be explored in detail the next section under the theme of “Communication”.

Communication issues

Communication when accessing, navigating and using health and care services was a strong theme within conversations. We heard about the importance of clear communication, and importance of being offered and provided with interpretation support. We also heard how the quality of communication by health professionals, impacted on experience of care.

➤ Language barriers and use of interpreting support

Some interviewees faced language barriers, especially those individuals who were newer to the U.K., and older people who had not been able to learn English. This affected both access to and experience of health and care. Not all were aware that they could make use of interpreters, or that this was available or should be offered¹. Most commented on using support of family or friends to help them understand. Interpretation was valued, but not always offered by health professionals.

- **Dependent on family and friends to interpret**

Despite NHS guidance stipulating that family or friends should not be used for interpreting, this was common, and when not available could be problematic:

¹ See: [Language interpreting and translation: migrant health guide - GOV.U.K. \(www.gov.U.K.\)](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/604222/language-interpretation-and-translation-migrant-health-guide.pdf) Where language is a problem in discussing health matters, [NHS England](https://www.nhs.uk/) guidance stipulate that a professional interpreter should always be offered, rather than using family or friends to interpret.

The older generation are very much dependent on their, on younger people to translate for them, when they go to receive services from the NHS ... I hear for certain appointments, they also attend to provide the translations... (Albanian man, 40's)

At the beginning my husband was with me every time, and he helped me ... I had some essential English ... my husband translated for me (Albanian woman, 30's mother)

We made the registration and (husband) was the one who spoke in my side, he helped me ... but the following years, the first years when I had an appointment with my doctor, that I could not explain the complaints I had (Albanian woman, mother, 40's)

- **Valuing interpretation support**

Comments showed that people valued the role and offer of interpreters in their interactions with NHS services:

I know people, they don't talk, and they don't have a partner or family, so it is very good to have an interpreter and they can talk more rather than waiting for families or friends to translate (Albanian woman, 30's mother)

Have had ... interpreter by the phone, has been very good, usually those persons have been I believe, responsible people and reasonable (Albanian woman, mother, 40's)

Lots of Albanian they speak English but they don't understand ... it's good to have interpreters ... or a writing interpretation ... especially in house care... family interpret all the time (Albanian woman, 20's)

Now no, I am not asking for interpreter, I don't speak like that but at least they understand me ... I know what I have to tell and to speak about (Albanian woman, 50's)

- **Comments on quality of interpretation support**

(Good) except one man that I don't understand ... I don't understand the way he spoke in meantime that I was showing my concerns that I had ... he was, was the translator on the phone, was a little bit arrogant I don't understand the reason why (Albanian woman, mother, 40's)

- **Not always offered an interpreter**

The fact that I'm not good with the English language should be, should be that they help me in a way that I can manage to understand that why (Albanian woman, mother, 40's)

➤ Communication in care (dignity, respect, explanation)

Whilst language and uncertainty about interpretation support presented barriers to accessing, using and navigating health services, comments were also made about the quality of communication when receiving care. Good communication in care, including having clear explanations of treatment, choice, and feeling listened to and respected were important factors in people's experiences of the care they received.

- **Clear explanations and communication**

Comments showed that people valued clear communication and explanation of the care they were receiving:

(At the clinic) Everything went perfectly well, the place was nice and clean, people were polite, and I was explained in every stage to what's happening, the procedure was supposed to be not very pleasant, but it was ok, I just came out of that very pleased (Albanian man, 40's)

(Maternity services) The communication was good but what I find something was not ... I think the midwives should be more talkative to me as I didn't know how it is, I had read a lot of information, but I think they should not have let me have all the gas, as it made me weak ... she was telling me, "you are doing very well" but not telling me to stay awake, alert, and what the gas would do (Albanian woman, 30's, mother)

- **Feeling listened and communicated to with respect**

Respect and being listened to was also important:

I was treated with respect (at the clinic), everybody was polite, and it was a very good experience, I can't see how can get any better (Albanian man, 40's)

I was listened to (by the GP), I've got nothing bad to say (Albanian man, 40's)

Good, kind and clear communication could be empowering and have a huge impact on experience of care, as one Albanian woman recounted in her experience of giving birth in hospital:

The doctor was very good at communicating, she explained as I had to decide if to go for a Caesarean or normal ... I wanted to try a normal, but I had a very bad experience with the first one, so I talked with her and she said "I've got your history, and I think you can do it by yourself" ... I have read it is good to try a normal birth, so I said, "I will try by myself", it was WOW! I went to the hospital for two hours, I got my baby, I couldn't believe it, I was walking, going to the loo and shower ... it was so easy! The midwife was very good, and I had a health visitor who came to my house ... she was wonderful (Albanian woman, 30's mother)

- **Feeling not heard or listened to**

Others commented on the negative impact of feeling that they were not listened to, not heard when asking for help, or that their experience and insight was not taken seriously by health professionals - especially when the issue was indeed serious:

I was upset, like, nobody was listen to me, not nurses, and no doctors, nothing, and they found out that I actually had a serious condition, it was like the only thing I got was an apology ... I was so sad because I was all by myself, no body by my side ... I thought I was going to die here ... and what are they doing, what is that doctors not trying to save my life, and how does the apology make that ok? (Albanian woman, long term health conditions)

Cultural competence on the part of health and care professionals was seen as key in making people feel understood and respected:

I think the services are good, I think that workers that working in services maybe need training to be more compassionate towards different backgrounds to cultures ... and that is the very important part what they do, so like the GP, and doctor they are compassion ... and dentist, and I hope that they have no so complicated but maybe they work hard ... but to understand the background of culture (Albanian woman, 20's)

Views on using NHS health and social care services

People spoke about their experiences of using NHS and social care services in general, as well as speaking about support from specific services they had received. Most were positive about the support they received from the NHS, from caring professionals.

➤ **Positive experiences**

My personal experience with the NHS has been rather positive, I was worried about something, I went to the GP to explain my situation and just a few weeks I received an appointment in a clinic ... (Albanian, man 40's)

I have had a hard life, no woman has had a life like that. But if I did not have a social service, if I didn't have the government, council, doctors, hospitals and all, I feel like I was born a second time in this country ... they have reduced my stress, they have me life ... I don't know ... how to repay (Albanian woman, 50's)

It has been good to the extent that whenever I needed health advice or to see a doctor, I was heard, given an appointment, or appropriate advice (Albanian, woman, 25-49)

For everything I am satisfied because they have sent me to hospitals, I received medication for cancer, with all worries (Albanian woman, 50's)

Some expressed huge gratitude for the care they had received:

They have given me medicine and pills and they are staying ready for me ... God bless them, God bless the England ... We who were in trouble, really suffered, they helped us. Well with some problems of course because nothing comes if you are not tried a little (Albanian woman, 50's)

One commented on awareness of and impact of lack of resources within the NHS:

NHS, I don't see a problem with except recently they don't really have enough resources, and I can see that's a problem ... they can be quite slow (Albanian woman, 20's)

➤ **Experiences of specific NHS health and care services**

In addition to the thematic comments about services throughout the report, people gave insight into experience and views of specific NHS health and care services.

- **GP care**

Views on GP support included positive comments, but also reflected on the current challenges of getting to see a GP:

I've been to the GP it has been very straightforward, we booked the appointment and I was seen fairly on time (Albanian man, 40's)

We saw a Doctor by phone, it was reasonable (Albanian woman, 30's, mother)

It takes such a long time to have an appointment for something simple like a blood test or a regular check-up (Albanian survey respondent)

- **Hospital - general**

I had to wait (at) the hospital for such a long time cos they didn't believe me what's happening, so I was waiting 48 hours, I wait for the doctor to come and see me. Even though I told them what's happening and how

critical was my situation. They only came and gave me paracetamol (Albanian woman, long term health conditions)

(At A&E) recently the paramedics were very nice, helpful ... it did take a long, long time them to arrive ... we have to wait three hours to arrive, but the female paramedic was not very sensitive (Albanian woman, 20s)

- **Hospital - maternity care**

Whilst previous comments illustrate the impact of positive birth experiences, other comments about maternity care were mixed. What we heard again emphasized clearly the importance of communication and being heard within health care settings, and indicated negative impacts this could have on women when this was not present:

Generally, I am happy with NHS services ... there are some little things ... not good memories ... I remember when I gave birth, I went to give birth and they turned me back because they don't have places ... it was August and most of the staff were with holidays and in place when I had booked (John Radcliffe) there wasn't staff. They gave me 4 pills, and they turned back at home, they said to me that "you are not ready to give birth". I was ready to give birth, I was sure, because I felt cos it was my 4th child, I had my experience ... I was ready to give birth. They told me, "No, you are not ready ... go at home, and you can have a birth for two or three days" ... at home I had 3 other children and my husband. ... I got up from the bed I had terrible pains, my husband called the taxi with my insistence, because he don't ... keeps saying "Don't be like that ... you are exaggerating, you have time, you have 3 days to gave a birth ..." (at the hospital) got a wheelchair and just entered the delivery room and gave birth ... did not last even ten minutes, and I gave birth. It was an experience so bitterly for me, I just can't forget that image that my children saw me with so much pains, and I who was sitting on the floor at home" (Albanian, woman, mother, 40's)

- **NHS Dentistry**

Comments about dentistry were also mixed. Some noted the expense of treatment, and long waiting times for appointments:

I haven't used dental care recently from the NHS, you know, I've only used it a few times since arrived in U.K. and the services are very basic, sometimes a waste of time really, because unless you have to pay, became really good service with NHS, that's my general opinion ... I've had a few check ups, and the rest of the treatments I had to pay it myself ... (Albanian man, 40's)

I haven't seen any dentists ... my eldest daughter had a tooth coming out, and needed fixing, it was very hard to get help ... as actually for the dentist we wanted to go back to Albania as it was better ... many people go back to

*Albania for the dentist as it is cheaper and they do very good work
(Albanian woman, 30's mother)*

*I've never had any issue with my dentist, he explained what he is doing like
he is teaching you, and my dentist also have an Albanian working for them
to help for the translations (Albanian woman, 20's)*

- **Mental health services**

Both community members indicated that there were barriers to accessing and using mental health services:

*I've seen lots of services in Oxford for mental health, but people have
problems, "if I go there, its official" mental health is something seen as
bad by the people, people don't understand and are afraid about talking to
people about their problems ... the stigma is very strong (Albanian woman,
30's mother)*

*I think the mental health is not taken seriously now ... I think that they
don't know what exactly are, the available for them (Albanian) and they
might be embarrassedand they can be anonymous ... (Albanian woman,
20's)*

*There should be more options in Oxford for mental health advice,
counselling and therapy that are free. Our health system shouldn't give us
anti-depressants as the first option to deal with issues. Talking space is the
only free mental health service and can take months to be referred to speak
to someone...months!! They only have two options available ... one to one
therapy for extreme cases of depression or cognitive behaviour therapy.
And those are not the only therapies to deal with depression anxiety and
other mental health issues. Specifically Albanian community in Oxford I
would say deal with depression very differently due to shame brought by
other Albanians. They tend to mask their depression with cultural beliefs to
make sense of how the world works which can sometimes lead to terrible
situations. As a culture we don't acknowledge mental health and therefore
never look for coping mechanisms. (Albanian, survey respondent, woman,
25-49)*

- **Physio MSK services**

*Having some neck problems, I can see for the GP it is easier just to give pain
killers, and not physio ... I would like not to have been given the
prescription for the drugs, as the pain killers have opium, and I said I can't
use them ... (Albanian woman, 30's mother)*

*I was referred to Healthshare, (Oxfordshire MSK provider) I saw them twice
face to face, there is a waiting list ... compared to others I know, they were*

waiting a long time for Healthshare, mine was quite quick, but I heard from others complaining about the long queue, and they are taking a lot of painkiller medicine to manage ... (Albanian woman, 30's mother).

Saw the physio by phone, I know what exercises I am trying to do, it was helpful, Healthshare has the website with exercises, so if I follow them it is good, depends on if I have time, I am only doing when sick and not every day ... but I think people find it better to go to the doctor ... and to do the exercises together, its more the psychology (Albanian woman, 30's, mother)

Wider factors influencing health and wellbeing

Interviews with members of the Albanian community, highlighted the significant impact of wider factors on health and wellbeing. Living in Oxfordshire was often hard, with sense of insecurity across housing, immigration status, high cost of living, insecure jobs, and experience of overt discrimination when navigating the system.

➤ Jobs and housing

I lost my job because of my illness. And I had to go and sign up for all the benefits at the job centre. I was treated so inhuman ... I was homeless, jobless, I couldn't have nowhere to stay, and ... even a criminal wouldn't be made to feel like this ... (Albanian woman, long term conditions)

People are doing lots of jobs, they want to help the family in Albania, and for themselves, they have to live and pay for living ... it's difficult (Albanian woman, 30's mother)

In that moment my child was born, they came, was the health visitor that she saw the environment where I lived with my children. It was, was horrible environment, with two little kids there. I remember that mould, the wall was mould up to the ceiling, all the house was like that, the kitchen, living room everywhere and, she said that cannot, it is impossible that a newborn baby live in a dirty place and outside living standards. Yes, and they took us and sent us to the hotel (Albanian woman, mother, 40's)

Housing is a big issue, people are sharing houses, living in bad conditions with children, babies (Albanian woman, 30's mother)

➤ **Immigration issues**

Most people with settlement are ok, with status, they work and are hardworking, but the other people are struggling and waiting to hear (from immigration) ... some have been in immigration centres, young people come here, with sacrifice their lives ... by lorries, finding ways to come, and paying lots of money to come here (Albanian woman, 30's mother)

A lot of the challenges Albanians face are due to immigration status and then the social structures - work, benefits, housing are key to mental wellbeing and social care (Albanian woman, 25-49)

I know people are waiting to hear from Home Office for paperwork, and getting stressed, depressed, and getting painkillers or drugs, and are sick, and not good wellbeing ... they want news from the Home Office, you can't imagine how people are waiting, waiting for years, and don't want to do anything ... To look after themselves (Albanian woman, 30's mother)

Many people have been more than ten years here, and don't have status ... Some may have visa, but they find themselves working in car wash, and sometimes struggling with paying if not allowed to work (Albanian woman, 30's mother)

➤ **Experience of discrimination**

Albanian interviewees, described the impact of encountering overt discrimination when engaging with the system:

I needed some help from housing, as I was on my own with my two little ones, my husband away, I had run out with paying rent ... I asked housing to help me with the rent ... it was a nightmare, the most bad thing I have experienced in this country, they didn't help me at all, they just said "you go back to Albania", I wasn't working, my children were babies, and they humiliated me, I couldn't believe they would treat me like this (Albanian woman, 30's mother)

(Job Centre) going through the questions, and he turned and looked at me, and he saw my handbag ... "if you can actually afford a handbag like that, I don't think you need benefits" ... I don't understand why I have been asked that kind of questions, for what? And then he goes to me like ... "Oh you can go back to your country and get treated" ... I've been in England 20 years,

and I've been working ... I respected, the law, and I knew that if I needed help I would get it, but I never knew that somebody ... would actually say "why don't you go back to your country" (Albanian woman, long term conditions)

... For me it always has been the discrimination I get and how that makes me feel it has made me very close down to myself and afraid of speaking out ... It would be good if they are a bit more understanding and less criticism towards people and treat them equally (Albanian survey respondent).

➤ **Impact of COVID-19**

Some are suspicious of the vaccine, as don't believe it ... and have lots of questions. The council did a webinar and answered lots of questions ... but at the end of the day, they should have information to help them decide (Albanian woman, 30's mother)

I've been neglected a bit by the doctors right now, cause has been a very difficult time with Covid, so I can't see the doctors face to face, but only by phone. I'm jumping from one treatment to another, it's just like, it's hard not knowing like what I'm doing or how long I've been doing for, or anything like that ... it will be nice like if I can get the doctor to speak to me to say you know ... "this is how long can I go, this is how it can happen" cause it's difficult even for me with this illness, it's not something easy to live with (Albanian woman, long term conditions)

It's been a great difficult because I had to be locked in the house, (not) go out anywhere, and it was much more scared cause when this started I had doctors phoned to me and say to me I have to stay in and be really careful because ... I would catch the virus. It would be really, really life threatening for me. And I had to take extra precautions, stay in my room, not even come downstairs, like to interact with other people ... alone. I didn't have any support at all (Albanian woman, long term conditions)

The council dropped food for me ... they phoned me up and asked me how I am coping with food ... it was difficult, cause I can't go nowhere, and I couldn't keep asking somebody to come and drop me food cause they need it money, and I couldn't get out to get money to give them ... the city council brought me lots of food. The only time I would go out of the house was when I would go to get treatment. (Albanian woman, long term conditions)

Raising concerns and being heard

We asked people's views on raising concerns about NHS and other services, and on being heard. None of the participants had heard of the CQC and few knew how to comment, give feedback or complain about treatment and care - or that it was possible. Whilst interested to hear about what the CQC offered, and to understand the role of both Healthwatch and CQC, there were a number of barriers expressed to coming forward - of information, cultural viewpoints, and concern with repercussions:

➤ **Knowing how and where to raise concerns**

(Complaint?) No! for God's sake, no, I did not know where to do it, I just asked for the manager to speak with ... I did not know (Albanian woman, 50's)

I haven't complained, I remember being asked for a review and I sent it back ... via text message (Albanian woman, 30's mother)

In fact, we don't, we did not complain because we had nowhere to complain this is the truth and I don't know ... no we don't know how to make a complain, as far as I know there is no office ... (Albanian woman, mother, 40's)

➤ **Reticence or fear in coming forward**

Albanians by nature they don't like to ask for help ... (Albanian woman, 20's)

When I went to an English class for the first time, we were leaning about how to write a complaint letter... she was asking "what would you do to complain about a shop where you tried to buy a pair of shoes?" ... "I would go to another shop" ... "No, you have a right to complain about the service because you are not in Albania" ... (Albanian woman, 30's)

Albanian speakers noted that experience of coming from countries where it was dangerous to speak out, or challenge authority, made people fearful:

In communism they can't make any complaint ... if you don't have anything to eat and you complain, you will be put in jail and called a propagandist (Albanian woman, 30's)

➤ **"Anything we are given should be appreciated" ...**

Never can I do it (complain) to England in this state (system), I can't do it because they accepted us, they opened their arms to us, they opened the door to us, they helped us, they sheltered, they have done everything for us (Albanian woman, 50's)

We need to be grateful for everything and not make demands ... we came into the country, we are living here, and need to know the language, the culture ... it's asking too much of the government to do this ... Albanian people can't ask help from government, when we were in communism we were more helping each other in the community (Albanian woman, 30's)

➤ **Fear of causing problems or harm**

"I don't want to make problems" (Albanian survey respondents)

(What would stop you complaining?) I was sorry because they helped me, you know? I didn't feel that way to report them, because I feel sorry for them, because they help me lots ... they help me lots but sometimes ... all these have done for me, I still cannot speak, my soul does not allow me to say bad word about this country ... they still do not owe us nothing, so we have to be happy for what they have done (Albanian woman, 50's)

➤ **Fear of repercussion**

Even though it can be anonymous, they still think someone will find out and tell ... they feel a sense of distrust (Albanian woman, 30's)

(Complaint?) It has stopped me so far as I thought it would affect the way they treat me (Albanian survey respondent)

➤ **Will speaking up make any difference, and will I be heard?**

No matter what you would say, no matter when you complain, the complain would go into the bin and they wouldn't take it seriously, they wouldn't, was really hurt me cause when I wanted that to listen to me they just like, close the door and were like "no we are not going to listen" (Albanian woman, long term health conditions)

I have actually got in contact with somebody to help me to make an official complaint, cause it was time about me to actually for them to listen to how I feel and why I am feeling like that ... I just hope that somebody will actually hear my voice. It's hard for me cause I've got no, I can't do it myself, I've got somebody else to do it for me, and hopefully my doctors will listen what is happening and take some actions towards it, so not suffering anymore, and don't feel like, nobody ... (Albanian woman, long term conditions)

How better to hear the voice of seldom heard communities?

When asked about how better to engage and reach out to members of their community - to support them to raise concerns and share experiences - anonymity, accessibility, and reaching out to where people are were seen as important.

If NHS can produce Albanian language materials, that might be some value potentially for Albanian speaking populations ... if information is available in Albanian it might encourage to actually read it, take actions (Albanian man, 40's)

I think having some anonymous questionnaire, asking them options, what you do know is anonymous, what they will do, I think the most important thing is anonymous because some people would be more encourage to tell the truth (Albanian woman, 20's)

If NHS organises some information base, for communities, they could have a day for each community area, and they could have stands in a populated area, high traffic areas with pedestrians, where if they are visible, sort of trying engage with the public ... and specifically with a particular group or particular day ... they could gain some attraction and encourage the Albanians to be more participant in taking/ giving information, you know exchanging information with NHS ... (Albanian man, 40's)

Cultural competence, respect and understanding of the background, culture and nuances of different communities was also seen as essential in fully enabling people to have a voice.

We are sometimes mistaken for East Europeans, people think we are Romanian, Polish or Bulgarian ... so it's a shame we don't have any way to raise the voice (Albanian woman, 30's mother)

Healthwatch Oxfordshire working with community researchers

Healthwatch Oxfordshire decided to approach this work by recruiting community researchers. This built on previous engagement approaches we have taken in working alongside communities, to identify together issues of concern, and to develop and carry out collaborative research that builds on, values and recognizes, skills and knowledge existing within communities themselves. (See for example,

recommendations in the Healthwatch Oxfordshire report “Oxford’s new and emerging communities views on wellbeing” (2021) with Oxford Community Action).

Working with community researchers can be a positive way to build trust, and to access, and support the voice of seldom heard communities to be heard. It brings strength in that researchers can navigate grassroots community networks, bringing local knowledge and language skills, as well as acting as intermediary with the wider system.

However, whilst hugely positive, this approach takes time and needs to be properly resourced - including providing organisational support with planning, recruitment, training and mentoring. There also needs to be appropriate value, recognition or compensation of the work undertaken by researchers and community themselves, and for recognition of need to invest and build a sustainable resource. In addition, communities need to understand that such work will have benefits, is not purely “extractive”, and understand that raising their voice can make a difference.

Appendices

Albanian community in Oxfordshire

Albania has a complex political, social and cultural history. Whilst 3.2 million people live in Albania in 2021, the Albanian diaspora stretches worldwide, including within neighbouring countries, the U.S., Europe, U.K. and Canada. Between 1991 and 2004 over one million people left the country. Driving forces behind emigration include ongoing challenges of economic hardship, and political instability. Whilst some Albanians in U.K. have received settled or refugee status, work visa, others spend years within the immigration system, awaiting Home Office decisions. Some Albanians have arrived in U.K. risking difficult and dangerous trafficking routes.

“Albanian people are traditionally very close to their families ... and they don’t expect the government or another one to look after them, we are very knitted together ... the people are strong, and they are positive, even if they have problems in their lives ...they are working hard, to try and do their best” (Albanian woman, 30’s mother)

Key facts and figures include:

ONS 2011 Census and ONS U.K. Population 2019-2020

According to the Office for National Statistics (ONS) 2011 Census:

- There were 440 people in Oxfordshire who identified Albanian as their first language.
- There were approximately 1,670 Albanian nationals living in the South-East region (*note this data is not available at Oxfordshire level*).
- More recent data at country level from the ONS U.K. population by country of birth and nationality 2019/2020 shows that there are approximately 31,000 Albanian nationals living in the U.K. (18,000 males and 13,000 females).

Department for Work and Pensions National Insurance Number (DWP NINO) Registrations to adult overseas nationals entering the U.K.

Since the period 2015/2016 to 2020/2021 ending in March:

- There were 389 National Insurance Number registrations from Albanian nationals in Oxfordshire.
- The higher number of registrations was recorded in the 2019/2020 period ending on March with 149 registrations.
- During the 5-year period, Oxford City had the highest number of registrations with 264, followed by Cherwell with 98.

Pupil Census 2020

According to the Pupil Census 2020, in Oxfordshire:

- There were 287 pupils who registered their main language as Albanian. Of these, 158 Year 1-11 students were based in Oxford.
- 42 were located in Cherwell, 220 in Oxford, 3 in South Oxfordshire, 18 in Vale of WH, and 4 in West Oxfordshire.
- Of those pupils, 147 were males and 140 females.

Albanian nationals currently represent the highest percentage of foreign nationals in custody with more than 1,500 in prison in England and Wales - around 10% of overseas criminals in jail (Gov. U.K., 2021)

Sources:

- DWP - NINO registrations to adult overseas nationals, Stat-Xplore, 2021
- ONS - 2011 Census - QS213EW Country of birth (Expanded), NOMIS, 2011 (note this data is not available at Oxfordshire level)
- ONS - Population of the U.K. by country of birth and nationality 2019/2020, January 2021.
- Oxfordshire County Council - Pupil Census, January 2020
- BBC Country profile Albania. <https://www.bbc.co.U.K./news/world-europe-17679574>
- Home Office. Country policy and information note Albania: human trafficking. Sept 2021. <https://assets.publishing.service.gov.U.K./government/uploads/system/upl>

oads/attachment_data/file/1026093/ALB_CPIN_Human_trafficking_002_.pdf

- Home Office. Country policy and information note: Blood feuds. Feb 2020. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/865400/Albania_-_Blood_feuds_-_CPIN_-_v.4_.pdf

Healthwatch Oxfordshire

Healthwatch Oxfordshire hears what children, young people and adults have to say about health and social care services, whether it is praise, criticism or ideas for improvement.

We amplify the collective voice of patients and the public, so that service providers and commissioners take notice. We then hold these providers and commissioners to account on how they use what we have told them.

Our other reports, films and insight of relevance to this report and to reaching seldom heard voices can be found here:

<https://healthwatchoxfordshire.co.uk/our-work/research-reports/>

Including:

- *Thank you for asking - Boaters' views of accessing health and social care services in Oxfordshire*. February 2020.
- *Asian Women's focus group* - May 2019.
- *Men's Health*. 2018.
- *And other "Project Fund" reports*.

For more insight into engaging with communities, see Healthwatch Oxfordshire's report "*Oxford's new and emerging communities' views on wellbeing*" January 2021 - community-based research with Oxford Community Action.

This gives insight into engaging with communities to build responsive health and care services for diverse and multi-ethnic communities - with equity, trust, better access, and cultural appropriateness - there needs to be a process of *continuous ongoing dialogue* involving -

1. **Better community engagement** - health and care providers to engage in an ongoing open dialogue and relationship with communities - working as equals, reaching out, building trust over time, to understand, address and acknowledge barriers and build solutions.
2. **More appropriate and responsive services** - this ongoing dialogue and community engagement will lead to deeper understanding of need and support development of services that reflect diversity. Services will be more appropriate and responsive, offered in a range of formats,

approaches and in diverse settings, working in partnership with community networks. Diverse communities will build trust and confidence through seeing themselves and their concerns reflected in wellbeing, mental health, and wider health services as a result.

3. **Improved information and access** - through this dialogue and seeing development of responsive services, there will be improved access to services by diverse communities. There will be engagement in service design, and development of communication, information and messaging that is culturally appropriate, using a variety of formats- including language translations, video and visual messaging, face to face contact, building on community and faith networks and links.

To learn more about the role of the Care Quality Commission visit:

<https://www.cqc.org.U.K./>