

Barriers to health and social care services faced by people on low incomes in Oxford

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Executive summary

This report is based on questionnaire responses from 206 Citizens Advice clients and 14 in-depth interviews with people who indicated a poor experience of health services. We found that there is high uptake of health care services, particularly GP and pharmacy services, with high average experience scores. Level of income was not found to correlate with service experience, which was broadly the same across incomes. This report focuses on the experiences of Citizens Advice Oxford clients who reported poor experience of healthcare services with the aim of further understanding these experiences and highlighting how services might be improved for this group.

Our main findings indicate:

- 13% (27) respondents stated that they did not access the health services they need, with language and lack of service provision cited as the main reasons;
- Participants stressed the value of good interpersonal relationships with health professionals such as GPs;
- Some participants expressed how they were reluctant to tell their GP about negative experiences of care and how care might be adjusted to their particular needs, such as with regard to religious beliefs or pain;
- Participants expressed that the requirement to repeat their medical issues to different healthcare practitioners regarding the same issue caused frustration;
- Lack of GP continuity was particularly difficult for people with long term health conditions;
- Participants raised issues regarding the quality of communication they experienced within health services, particularly around clarity and consistency of information. Some participants did not understand their treatment and the prescription of particular medications;
- Information was also found lacking on surgery opening hours, choice of services and treatment options conflicting information from professionals, and lack of information on the status of referrals for specialists;
- Some participants expressed how their experiences of healthcare services cause them increased anxiety and the need to travel long distances for specialist treatment led to some participants being financially worse off;
- Participants placed a premium on the 'friendliness' and empathy expressed during their care. Many said this made a difference to their overall experience and helped to understand the reasons why particular treatments are prescribed.

Our findings indicate that people who are vulnerable and on low incomes are struggling to access a 'one size fits all' service. However, many of the barriers to positive experiences of care raised by participants are not exclusive to those on low incomes. Addressing the causes of these poor experiences are therefore likely to improve satisfaction with NHS services as a whole not only for those in these groups.

Recommendations

These findings invite service providers to become more aware of the needs of patients on low incomes and ensure healthcare services are responsive to those needs. Specifically, we recommend:

1. Ensuring continuity of health practitioner for vulnerable people, particularly those with long-term health conditions such as mental health and chronic pain;
2. Improvements to the quality of 111 service, so that the first person to answer a call is able to provide accurate clear advice;
3. Consistent language/translation support is provided for people with English as a second language across all services and printed and online information is available in a range of languages;
4. Ensure patients feel that their feedback on NHS services is valued;
5. Provide clear information on service expectations and what options are available if patients feel that these have not been met;
6. Provide opportunities for patients to feed back their experiences in ways that do not require them to read and/or write;
7. Practitioners prioritise quality, friendliness, equality and respect in their interaction with patients over process and systems;
8. Provide patients with clear accurate information on options available, side effects, alternatives and waiting times;
9. Ensure access and options are appropriate to the patient's ability to engage i.e. IT, phone or travel;
10. Ensure that even when patients are willing to undergo a particular course of recommended treatment, the practitioner takes into consideration the added financial, time and emotional inconveniences that this might create and adjust options to make treatment as convenient as possible;
11. Ensure that GP hours are clearly communicated and surgeries are open long enough to meet the needs of patients in particular areas.

Introduction

During summer 2018, Citizens Advice Oxford conducted a research project commissioned by Healthwatch Oxfordshire to investigate the experiences that people on low incomes have of health services in Oxford.

Citizens Advice Oxford is part of a network of 288 independent charities throughout the UK. Our twin aims are to provide the advice people need for the problems they face, and secondly to improve the policies and practices that affect people's lives. We give free, confidential information and advice to assist people with financial, legal, consumer and other problems. Advice is delivered through drop-in sessions, by appointment, through our Adviceline phone service and via the Citizens Advice website.

We also undertake research and campaigns work to bring about policy change for the people who use our service, as well as enabling clients themselves to have a voice in influencing directly how policies and services are run.

86% of the 5,500 people per year that visit Citizens Advice Oxford are from low income households (income less than £1,500/month). Over the past two years our service has seen a 155% increase in clients requiring support with health-related benefits such as PIP and ESA, with many more struggling with lower level diagnosed and undiagnosed physical and mental health issues, a minority of whom we anecdotally know are not connected with their GP or have mistrust of health care professionals.

Health services are therefore a key area to explore in order to enable people on low incomes to improve their situation. Citizens Advice Oxford is well-positioned to provide an insight into this demographic section of Oxford's community. The aim of this research is to enable us to better understand barriers faced by people on low incomes experiencing health inequalities and draw together recommendations from people who are directly affected by these issues. This will help us to engage more effectively with health and social care providers and lead to better outcomes for our clients.

Definitions

By the term '*Health and Social Care*' we mean clients' use of the following services:

- GP surgeries
- Pharmacies
- Dentists
- Online/phone services such as 111
- Opticians
- Personal helpers at home (for example to provide personal care, housekeeping)
- Residential Care
- Hospital and Ambulance Services
- Mental Health Services

In this report we have tried to give voice to clients on low incomes and for that we have considered every participant with monthly earnings below £1499 to be on a 'low income' compared to the average £1915 monthly earnings of Oxford city¹.

'PIP', is an acronym for '*Personal Independence Payment*', the benefit for people with long term ill-health or a disability.

ESA, stands for '*Employment and Support Allowance*', the benefit for those who cannot work due to ill-health or a disability.

The social determinants of health (SDH) are defined by the World Health Organisation (WHO) as: 'the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life.' These forces include structures such as social norms, social and economic policies, and political systems.

¹ ONS data.

Background and rationale

Literature review

Health inequality has economic and human costs for everyone. The resulting shortfall in resources leaves the whole of society worse off, not just those living with worse health outcomes.

As highlighted by the World Health Organisation, Marmot review, NHS Five Year Forward Strategy and the Oxfordshire Health Inequalities Commission report, people in lower socio-economic groups are more likely to experience chronic ill health and die earlier than others. In addition, these health inequalities are preventable.

Poverty and poor living standards have been linked to health outcomes through what has been termed the social determinants of health (The Health Foundation, 2017). These social determinants of health are defined by the WHO as: *'the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life.'* These forces include social norms, social and economic policies, and political systems².

Social determinants are a combination of an individual's material situation, their behaviour and choices. Material deprivation impacts directly on physical health, for example through cold and damp living conditions. Material factors are also associated with mental health outcomes, for instance, low quality living conditions can lead to feelings such as stress, lack of control, misery, despair and hopelessness. These feelings have a direct impact on both physical and mental health.

The social determinants of health also inform health behaviour. If a person lives in a safe neighbourhood with accessible, clean, green spaces they are more likely to take exercise. It follows that those without close access to such services may avoid physical activity. Another example is quitting smoking, which is harder under circumstances of stress, unemployment, or housing instability. Improving local environments and reducing day-to-day stress would therefore increase the likelihood of improved health behaviours.

Evidence shows that social determinants of health indicate whether a person is likely to experience good health across all stages of life (The Health Foundation, 2017). A life course perspective highlights how health inequalities are developed at critical risk periods: preconception, childhood, working age and the last years of life. This approach indicates

² WHO, http://www.who.int/social_determinants/sdh_definition/en/ accessed 14/06/18.

that successful health initiatives are those that consider the importance of prevention and intervention at an early age, the capacity that families must help their children, and peoples' attitudes towards prevention.

Going deeper into the dimensions of the social determinants of health inequality, Marmot Indicators (2015) outline the clear difference in both total life expectancy and healthy life expectancy between men and women from the poorest and most well-off areas. Around 40-50% of the variation in health outcomes is driven and caused by unequal distribution of social and environmental factors (Marmot, 2017). These recommendations are improving child health prevention and diet and raise the awareness and/or means to do this, empowering every person to maximise their capabilities, create fair and good working circumstances, develop healthy and sustainable communities, strengthen the ill-health prevention and ensure a healthy standard for all. Thus, all service providers need to ensure that services are as responsive as possible. For example, discharge arrangements from NHS care need to be appropriately tailored for people who are homeless. Services need to be sensitive to the cultural norms and beliefs of patients from minority ethnic communities.

The latest information shared by the Office for National Statistics regarding life expectancy has shown a continuous gap increment over the last 11 years. It shows how even being just six miles apart the wards of North Oxford and Northfield Brook (in east Oxford, next to Blackbird Leys ward) reveal the huge disparities between people with different levels income and privilege in the city. Some of the stats revealed show how in the North ward, (Summertown, Walton Manor and Park Town) men can expect to live until 90, and disability-free until 74; whereas in Northfield Brook they die on average at the age of 75 (below the national average) and fall ill from 59³.

Rationale

Our service has seen a 155% increase in clients requiring support with health-related benefits such as PiP and ESA over the past two years with many more struggling with lower level diagnosed and undiagnosed physical and mental health issues, a minority of whom we anecdotally know are not connected with their GP or have mistrust of health care professionals. This can limit the effectiveness of the advice provided, since clients' ability to progress the issues that affect their lives and more broadly clients with borderline poor health and unable to benefit from health issue prevention and early interventions.

³ Oxford Community Foundation <https://oxfordshire.org/life-expectancy-differs-by-15-years-between-men-in-north-oxford-vs-northfield-brook/> Accessed 25/10/18

Methodology

This project was designed to allow participants to meaningfully engage with its design, undertaking and findings. In practice, this meant: being clear about the objectives of the research at every opportunity, seeking participant feedback on the analytical themes that emerged and holding a focus group to discuss findings with participants. The research methodology is structured to allow individuals to discuss their personal experiences of health and social care and the broad array of NHS services they may have used. This allows for a holistic understanding of experiences of health and social care to emerge that touch on a cross-section of NHS services.

This research aims to explore how people on low incomes experience health and social care with a mix methodological strategy. We used three principal data collection methods: questionnaires, in-depth interviews and a focus group.

Questionnaires

Questionnaires were given to Citizens Advice clients in the waiting room at Citizens Advice Oxford between 19th June 2018 - 28th August 2018 and at casework appointments [Appendix 2]. We aimed to receive 200 questionnaires to represent a cross-section of the 5,500 clients Citizens Advice saw during the fiscal year 17/18, securing a 95% level of confidence and an error below 7%. 206 questionnaires were completed. The questionnaire identified the different NHS services used (e.g. GP, pharmacy, 111) and the extent to which experiences of these services were positive/ negative [Appendix 1]. The questionnaire also collected participants' income which was used to screen participants for a follow-up interview.

Interviews

Participants whose income was below £1,499 per month and who indicated that they had negative experiences with one or more NHS services in the initial questionnaire were contacted for a follow-up interview. We conducted 14 in-depth interviews with eligible participants following the questionnaire responses. Interviews were held at Citizen's Advice Oxford and lasted in duration from 30 minutes to 1 hour and 30 minutes. One interview was conducted in Spanish and translated into English on transcription. Care was taken in the selection of participants to interview a range of Oxford Citizen's Advice clients representing a balance of genders and ethnicities that are broadly in-line with the Oxford population on low income. At the start of each interview, participants were told about the aims of the project and explicit written consent was given by each participant.

The interviews were structured around three broad themes relating to:

- 1) Patient experience of NHS services
- 2) Reasons for engagement or lack of engagement with NHS services
- 3) Recommendations for areas for improvement

Participants consented to their voices being recorded for the interviews. In one case when a participant asked not to be recorded, hand-written notes were taken. Recorded interviews were fully transcribed.

Participants were given a £15 shopping voucher for their time and any transport costs were reimbursed. Many interviewees expressed that they enjoyed participating in the interviews and were grateful that their experiences were being considered. Some asked to be kept informed about the outcomes of the final report.

Focus group

A focus group took place at Citizens Advice Oxford on Thursday 27th September 2018 once all interviews had taken place to triangulate findings. Five participants attended the focus group, all participants had previously been interviewed about their experiences. The focus group was led by the Participation Officer at Citizens Advice Oxford with discussion centred on the main themes that emerged from the interviews. Participants were given the opportunity to discuss these themes, add their own experiences and listen to others' experiences of NHS services. The focus group was audio recorded and the ideas discussed were used to organise the qualitative data in this report.

Focus group participants were given a £20 shopping voucher and lunch was provided. At the end of the focus group, participants described how they would be willing to participate in similar discussions in the future.

Analysis

The structure of the following report is a product of the themes that emerged from the questionnaires, interviews and discussion with participants at the focus group. The questionnaires have been compared with our client database and Oxford population for the demographic information and the rest of the questions have been studied with univariate and bivariate analysis. The data from the interviews was open-coded and individual experiences of the participants have been anonymised and used as case studies for particular issues. The analysis reflects areas of care that participants feel are working well and the areas they feel require improvement.

The structure of the findings is intended to shed light on some of these themes but does not specify their relative importance or priority.

The recommendations that this report makes are based on the issues raised by participants themselves.

Ethics

We gained written permission from all participants to use their anonymised data in this report. This was done by anonymising data from the questionnaires and analysing the data of all participants without a bias towards selecting individual accounts. For the interviews we provided all participants a consent form [Appendix 3] that explained in detail the purposes of the research, how their involvement would be used, and how the sensitive data is confidential.

Ethics have been considered not only when covering the ethical standards but across every stage of the research process. With this intention the focus group was done to give participants the opportunity to discuss the findings and provide a better representation of their voices.

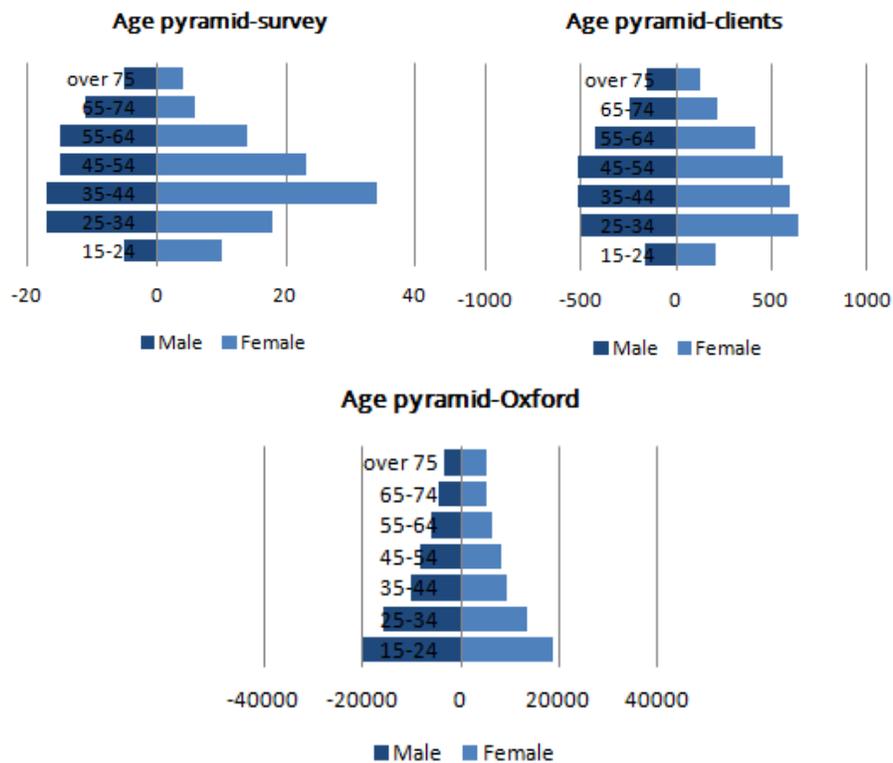
Quantitative Findings

In this section, we firstly review how accurately the sample for this research reflects Oxford population⁴ according to demographic indicators followed by an analysis of use of health services questions.

Age and gender

Figure 1 shows the age pyramids for those who completed the questionnaire⁵, the Oxford Citizens Advice client database and Oxford city population. Comparison between these three groups indicates that questionnaire respondents are older than the overall population, which is mainly due to the large student population which tends to access student specific advice provision rather than Citizens Advice.

Figure 1: Age pyramid of questionnaire participants by age group and gender N=194. Figure 2: Age pyramid of Oxford Citizens Advice client database by age group and gender N=5273. Figure 3: Age pyramid of Oxford population by age group and gender, ONS population estimate 2016, date published: 22 June 2017, N=135374.



⁴ Data taken from ONS, City Council and Census 2011.

⁵ Excluding no response

Income

As noted in the literature review, low-income populations are more likely to experience poor health outcomes. Table 1 compares the monthly income of the questionnaire participants and our client database and reveals that questionnaire participants' incomes are similar to the distribution of our client base. 79% and 75%, respectively, are from low-income households, with an income of less than £1,500/month. Around 50% report an income of less than £1000/month in both cases, and 15% and 22% less than £400/month.

ONS Average Earnings indicates the average monthly income for Oxford is £2,401. Based on this figure, 92% of the sample used in this report have lower than average incomes.

Table 1: What is your monthly income? Monthly income questionnaire participants and client database FY17/18, excluding no response. Totals and percentages.

Categories	Participants	Perc. %	Clients	Perc. %
Over £2,000	15	8%	215	14%
Between £1,500 and £1,999	23	13%	169	11%
Between £1,000 and £1,499	54	31%	359	23%
Between £400 and £999	58	33%	468	30%
Under £400	27	15%	338	22%
Total	177	100%	1549	100%

Health and income

38% (71) respondents indicated they had a long term health condition which is higher than the national average of one third of the population.

The table below shows a clear link between low-income and long term health conditions; the three categories with less than £1,499 per month present that over 40% of them have long-term health conditions whereas the two categories over £1,500 are 26% and 20%, respectively.

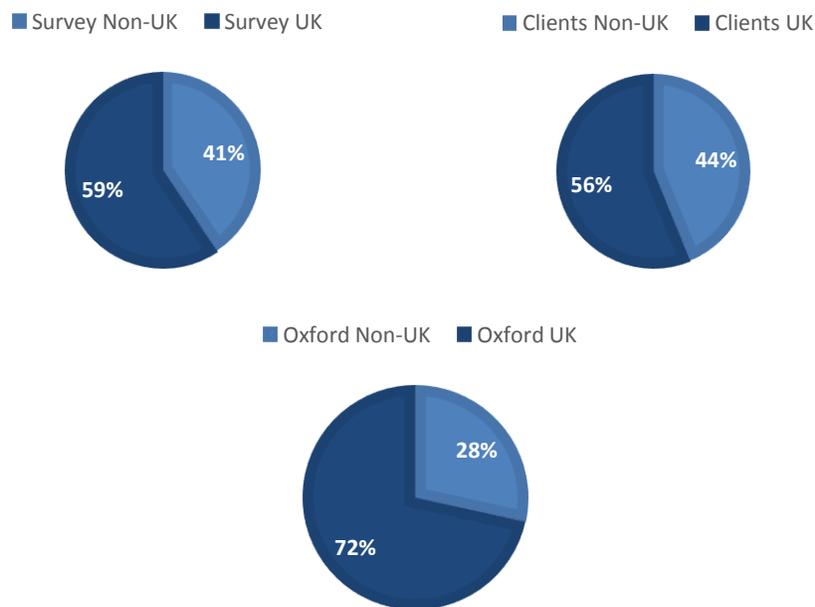
Table 2: Do you have a long-term health condition? Long-term health condition by income, excluding no response. Totals and percentages. N=188.

Categories	No	Yes	Yes %
Over £2,000	12	3	20%
Between £1,500 and £1,999	16	6	26%
Between £1,000 and £1,499	29	22	42%
Between £400 and £999	29	28	48%
Under £400	13	12	44%

Nationality

The final comparison is based on the nationality of the questionnaire participants, clients and Oxford city residents. The charts in Figure 4 demonstrate a similar distribution between the questionnaire participants and the client database with 41% and 44% non UK nationals compared to the Oxford population of 28% non UK. Participants who have a nationality that is not the UK are therefore overrepresented in our sample compared to the Oxford population as a whole.

Figures 4, 5, 6: Pie chart by nationality. UK and Non-UK residents. The questionnaire⁶, clients' database⁷ FY17/18, Oxford population, ONS census 2011. Percentages F4 N=202; F5 N=3575; F6 N=151906.



The most common nationalities among non-UK clients in the database are Poland, Portugal, Italy, Spain, Romania, Iran, Lithuania, Brazil and France. In the questionnaire, the same pattern is shown with Poland, Portugal, and Spain as the most common nationalities.

Summary

The sample for both quantitative and qualitative aspects of the research tended to have poorer health, lower income, older and more likely to be a non-UK National than the wider Oxford population and therefore has been effective in reaching people with these vulnerabilities.

⁷ Excluding no responses.

Uptake of service

As indicated in Table 3, the majority of respondents have accessed a health care service, most common were 96% (189) of those that answered stated they had accessed their GP or Doctors surgery and 95% that answered (163) had accessed a pharmacy.

Respondents were least likely to respond to the question for accessing mental health support with 28% not answering the question. Of those that did answer 28% said they had accessed these services, which is broadly in line with the national prevalence of mental health of 25%.

Table 3: Use of services by average experience score, rated 1-10 where 10 is very positive

Service	Average experience score	Used in last 3 months	Have ever used	Never used	Did not answer
Pharmacy	7.92	127	36	8	35
Ambulance	7.89	29	43	78	56
Opticians	7.70	46	64	40	56
Hospital	7.61	70	80	22	34
Online health information	7.48	28	31	81	66
GP/Doctors surgery	7.45	139	50	8	9
Dentist	7.42	62	76	25	43
111 phone services	6.83	36	37	81	52
Mental Health support	6.50	21	18	102	65

12 people stated that they had never used the GP or pharmacy, with four respondents not accessing either in all 12 incidences respondents were not of UK origin. Those who had not used the pharmacy were predominately male aged 24-35, this group also accounted for 50% of non-GP users with women aged 22-27 making up the other four non-users.

The most prevalent demographic indicator for non-engagers with other health care services was also nationality with non-UK Nationals accounting for 73% of non-dentist users , 60% of non-optician users and 58% of non-hospital users. Non-users of the 111 service were equally split by UK and non-UK and had no other distinguishing demographic features.

When asked directly if they accessed the services they need, 27 participants (13%) stated they did not access the services they need for their health. Of the 22 responses indicating why this is; seven people stated lack of availability of doctors or practitioners, four cited language problems, and two had not tried to access services.

Experience of services

Users of services were asked to rate their last experience on a scale of 1-10 where 1 equals very poor and 10 equals very positive. As indicated in Table 3 experience at the pharmacy was rated highest with mental health support rated as poorest.

Although the sample for those with average or higher than average incomes was relatively small we found no significant difference in experience rating by income.

Qualitative Findings

This section draws together key themes supported by verbatim statements arising from 14 interviews and a further focus/triangulation group with five interviewees.

Accessibility and consistency of services

GP service

Experiences of accessing GP appointments varied widely, with the most positive examples including rapid telephone access to a trained healthcare professional to triage their problem and book an appointment. Less positive examples involved lengthy waits for either an appointment or call-back, having to engage with non-medically trained staff to discuss the urgency of their situation, or being transferred through multiple contacts and having to re-explain their situation before receiving an appointment.

Lack of 24-hour access to GP services was also seen as a problem for some people, particularly those in work. Two participants reported that emergency/out of hours access to GP services is working well but one would like to see GPs open longer hours (past 6.30pm) and over the weekends. It seems that information about out of hours' services had not been widely received and that varying opening times for different surgeries causes confusion.

Emergency and specialist services

The length of time waiting to receive specialist appointment was highlighted. One of the interviewees called for an appointment after receiving a referral letter and was told to wait. After three months they had no news about an appointment and had not received treatment for the medical complaint as the GP said it must be seen by a specialist.

One participant said that the emergency ambulance came quickly, and the JR hospital emergency treatment was good. However, another said they faced difficulties and delays in emergency treatment. They called the ambulance in the evening because of pain; and were taken to the Abingdon clinic where they waited an hour to see a doctor. They were then sent to the JR where the machine was broken and where then sent onto the Churchill. This person stayed in hospital for over two weeks.

111 service

Participants described long waits for calls to be answered and having to respond to seemingly irrelevant questions before being able to discuss their problem. One participant was transferred four times and then had to retell their story over and over again. "It's not easy. It's very, very difficult'. For those in pain, or with difficulties understanding English, this caused frustration and prompted one participant to claim they would avoid using the service altogether. *"If I can avoid the service, I do"*.

One participant described the high quality of advice he received from the 111 service despite his frustration with a lengthy wait time.

"very, very happy experience never ever, ever problem ... emergency is very busy, 111 ask long, long questions I think they spend long time in this service but 111 in the end is a good service but its long time and lots of questions. Sometimes say hold the line long time I have a bad experience about that because my son no well."

Case study 111 service, timely access

M, for whom English is a second language, was positive about the experience of health services, but had a difficult experience with the 111 service.

M's child fell and banged their forehead whilst playing. When the child complained of feeling dizzy M was concerned and tried to get some advice, the GP was closed and M was reluctant to go to the JR because of hearing of long waiting times. A friend informed M of the 111 telephone service.

M was passed from one person to another, four times. Each time asked the same questions and then instructed to wait 30 minutes for the doctor to call back M stated he would avoid using the service again and suggested that it would have been better if there had been no transferring from one person to another.

IT

The use of technology to access services was polarising. The shift towards online GP appointments was challenging for those without IT equipment or internet connection at home. Conversely, the use of electronic check-ins and text message reminders about appointments were felt to have sped up access to services.

Travel

Travel costs were a barrier for some participants. In one case, a letter offering alternative appointment locations was not relevant due to associated travel costs and time.

"Making an appointment and you are sent letters with all sorts of ridiculous choices it is really aggravating. I want one choice that is a good local service. That is the only choice I want. I am not travelling to Dundee for a physiotherapy appointment and to waste money on the organisational structures that (...) it is not a real choice. I'm sure that there are a very small minority of wealthy people with time and money to travel... I'm sure it is a choice... but it is not a real choice for most people..."

Another participant described how she paid several hundred pounds to travel for treatment in another city which when she arrived was not provided:

"I had so many pills from [another location], and then I had to pay for a taxi fare home. £300 it cost me. Anyway, it's all in the past. But they did not do anything there, I went all

that way and just sat there... and then the nurse...anyway it's all history now. I never saw anybody."

Choice restrictions

The importance of developing a personal relationship with an assigned doctor was highlighted. One participant recalls how their GP service was changed which meant she could no longer see her own GP; this was assigned by the surgery based on call-back availability and her preference was ignored.

Another participant became confused because they were told they had to change their GP surgery after moving to a new house. They felt this went against continuity of care:

"I don't understand this organisation because I think patients [should] have choice to which doctor they want to go and to which doctor to trust or you know very specific relation with somebody. It's completely strange to go open all your private, all your body."

One person's daughter was taken off the local GP register when she moved away to study, which meant that she couldn't access the family doctor when needed to on a return visit. No alternative was given –

"They just say 'we cannot see you', they like throw you out. I don't think that is good enough."

Case study regarding access to GP, language

N, for whom English is a second language, had experienced depression and anxiety which had been treated with medication in their home country. This anxiety returned in the UK when N was encountering stress associated with unemployment and debt issues. In addition, N suffered from chronic foot pain and then experienced rib pains following a fall.

N's anxiety became so severe during one weekend that they experienced tachycardia *"...my heart was going a thousand miles per hour"*. N was not sure what to do. They didn't want to call 999 because it might not have been serious enough – N was worried about being a nuisance. After trying unsuccessfully to find an open health centre online, N experienced *"... a bad day"* waiting until Monday morning until an emergency GP appointment was available.

Regarding the rib and foot problems, N compared the experience with that of visiting a GP in their own country where they would normally do an X-ray. N said that was more reassuring – in comparison with the experience here where the GP comes to a diagnosis without radiography.

N is positive about the experience of GP treatment – very friendly and the GP's use of Google translate was very helpful during the consultation. The GP shared the term in their language for the foot problem and encouraged them to look it up to understand more about it. The patient was also given a practical means of managing the problem and was told what the next steps could be if that did not work.

In general terms the patient's experience of the practice raised a few concerns. They were not clear who is their assigned GP; they had encountered difficulties with access to online appointments; and they had the impression that it is more difficult to see a specialist (a psychiatrist) or get tests (radiography) than in their home country.

N suggested that there could be improvements in the information about out-of-hour services. They were not convinced that Skype or video consultations would be very effective.

Communication

The quality of communication with NHS healthcare professionals was another area that influenced participants' satisfaction with NHS services. Less positive experiences included not receiving adequate explanations of treatments, or conflicting advice from different healthcare professionals, or simply not feeling understood or listened to. Participants also described examples of healthcare professionals going out of their way to communicate clearly.

Participant interviews revealed several distinct aspects of communication, specifically clarity, consistency of information, and repeated requests for information.

Clarity

Participants described experiences where healthcare professionals had failed to clearly explain treatment decisions. For example, one participant felt she had received no explanation about the side effects of her prescribed pain medication. Learning about potential side effects from friends rather than her GP undermined their already strained relationship, resulting in her ending her course of treatment without consulting her GP.

Clear communication was particularly important for those who struggled to understand English. Two participants identified language as a potential barrier to accessing services. One felt that if they were misunderstood, there would be a delay and no access. Another felt that their own self-research was restricted by language, *"I don't read it properly"*.

However, there were also examples of healthcare services successfully tailoring their approach to support non-English speakers. For instance, interpreters made available at short notice during hospital appointments, and a GP who made efforts to communicate clearly and translate terms that might not have been easily understood.

"The GP was friendly, and they used Google translate during the consultation which was very helpful"

Consistency of information

As with unclear communication, receiving contradictory medical advice created a similar lack of trust in healthcare services. For example, one participant described receiving opposite advice about catheter removal from a nurse, hospital consultant and his GP, which prompted him to question the training and skills of NHS healthcare professionals generally.

Repeated requests for information

Trust in healthcare services was further undermined by participants being asked to explain their situation multiple times. Participants perceived this as healthcare services either not reading records or not adequately sharing information. One participant with a mental illness described their frustration with being asked to repeatedly provide the same information. *“Often the case...that you explain everything to them... and then sometime later they will ask you to explain it to them all again... it’s a bit of a windup.”*

Delays in acquiring information

Patient experience was negatively affected by delays in hearing back from GPs and other healthcare professionals. One participant described how she waited in all day for a call back from her GP. The patient described how: *“it was not until 6 o’clock at night that I got a call, I had to wait in all day it was bad”.*

Interpersonal Relationships

Strong value was placed on the interpersonal relationship with health professionals. One participant highlighted how important his good relationship with his GP is for his health, and how he feels supported and not judged. Participants shared experiences where the personal approach could be improved.

Listening

One person said that the GP didn’t listen to them or address the problem they were asking about. Instead they focused on a blood test which was not something she understood the need for. He also didn’t introduce himself; *“he was lording it over me, they have not been listening properly. Not in a horrible way, but in sort of sarcastic way like ‘we’re the doctor and you’re the patient’ that sort of attitude”.*

Another participant described how negative experiences arose because of conflicting priorities between the doctor and the patient. One participant described how: *“You get to see who you get to see; you don’t get to see who you want to see and he was horrible, this doctor. He was horrible. He did not examine me, he argued with me about blood, he said you need to have a blood test. I said “I am quite happy to have a blood test but could you please look at my back, I’ve had it for two years. I wanted to see Dr X but now I have you”. Oh, he was horrible.”* According to the participant, these conflicting priorities are exacerbated by having multiple GPs with whom it is difficult to build a personal relationship.

Attitude

One participant said they felt unable to say how they really feel to their GP. He perceives medication reviews as a form of control. *"I get on the wrong side of her sometimes by being honest about some things and it is a tricky one that. I don't know if I'd want to upset her like that really."*

A former patient of a mental hospital felt that the staff have no empathy – they did not help at a time when he needed practical help to solve a legal problem; and *"they don't love people."*

Another had a negative experience with a psychiatrist who assessed him for the CMHT service (which resulted in his discharge). He said it felt like an interrogation – *"He was dismissive, disbelieving, he made me feel like a fraud. He did not know me."*

Participants placed a premium on the 'friendliness' of how they were treated when seen by healthcare professionals. One participant explained how the friendly attitude of nurses made a positive difference to their experience when they were in pain. When asked about what made their experience positive they explained: *"because it's friendly, it's the nurses about patients it's happy, its friendly, it's a talk to you about your cases and let me know what you can do. If you happy if you have pain, I think this is very important".* The participant also described how good experiences of the NHS depend on the positive 'vibe': *"when you go it's good because sometimes they give good vibe it's very important what they do".*

Respect

Being treated with empathy and respect underpinned many of the experiences participants described – both positive and negative. Positive experiences involved professionals listening and adapting the service to fit the needs of patients, respecting their knowledge and preferences, while negative experiences typically involved participants struggling to navigate a service that failed to see them as individuals. This was illustrated by one example where a pharmacist discussed a participants' private medical information loudly in front of strangers, undermining the participants' right to privacy.

"This was somebody from pharmacy I think in reception in my GP, they start to talk about my private prescription out loud, that was completely unacceptable"

Case study regarding unresolved chronic pain; medication issues; changes in GP practice

R is 70-years old and has been retired for four years. Previously in good health, R suffered an accident two years ago and since that time has been suffering chronic pain and feels that the health services have not done much to help. Aspirations for an enjoyable and active retirement have not been realised.

The pain control medication received from the pharmacy at the hospital R was referred to generated unwelcome side effects. R did not see a doctor on any of the visits to that hospital. After some months of difficulties, it was only on a visit to the dentist that R was told of the connection between her medication and the symptoms she was feeling (loss of weight and being “completely doolally”). R decided to stop taking the medicines and seek help from the local GP surgery.

R was unable to get an appointment with a previous GP (with whom R had positive experiences) or with an alternative doctor recommended by a friend. Their experience with the assigned doctor was not at all positive – R found him very condescending; he was not interested in what R was requesting (for him to look at the source of the pain) and he prescribed medicine without explaining anything about it. Once home, R looked up the details of the medicine on the internet and decided not to take it as it indicated the possibility of similar side effects to those R had previously been suffering. Since then R has been partially managing pain through exercise (encouraged by a neighbour) and taking aspirin. R has more recently been suffering from insomnia.

R’s experience of change in GP practice has not been at all positive. They have not received any explanation of why it’s not possible to see the original GP, and R is very concerned about getting referred to the doctor who did not treat R well. There are general changes to the way the surgery is operating and R does not feel informed about any of this.

This negative experience of the GP practice is affecting R’s current engagement with health services. R has been reluctant to seek help for insomnia or to take up the services being offered (optician, shingles check-up etc). Nonetheless, R is willing to try again with the GP practice but hopes there would be a change in the attitude of the doctor. R liked the idea of a practice care navigator and social activities such as group exercises.

Conclusions and recommendations

Conclusion

This project has explored the experiences of participants regarding their use, engagement and satisfaction of health care services.

Overall, there is high uptake of health care services, particularly GP and Pharmacy services with high average experience scores of between 7.4 and 7.0 out of a possible 10 for all services apart from 111 non-emergency phone service and mental health services which scored an average of 6.8 and 6.5 respectively. Level of income was not found to correlate with service experience, which was broadly the same across the income groups.

Access

Thirteen percent (27) respondents stated that they didn't access the health services they need. Language barriers or being a non-UK national was found to be the most common factor for those not accessing services, this non-engagement is further compounded by not being able to undertake self-research into their condition in their first language.

Contrary to this finding is the non-use of the 111 non-emergency phone line which was consistent across all demographic indicators. Just 58% of respondents had used the service and cited being repeatedly asked the same question, being passed to multiple operators and not being able to understand as being the main barrier to using this service again

Interpersonal relationships

Participants reported the value of good interpersonal relationships with health professionals such as GPs. Participants placed a premium on developing trustful, meaningful relationships with a single point of contact for their healthcare.

Key areas which emerged on this theme were the ability to communicate across language barriers, explaining information clearly, empathy, being listened to, and respect. Among the positive experiences that were raised was an example where interpreters being made available at short notice, and a participant that feels supported and not judged by their GP. Conversely some participants felt they could not really say how they felt to their GP or have their preferences heard and this undermined the effectiveness of their care.

Lack of continuity of GP was particularly difficult for people with long term health conditions, including mental health and chronic pain who expressed concern that the change meant they need to explain all aspect of their condition and treatment to date to secure continuity of care and was difficult for people to manage alongside their illness.

Being required to change GP surgery when moving to a new house or a change in circumstances was thought to be unnecessary and detrimental to continuity of care.

Participants generally placed a premium on the 'friendliness' and empathy expressed during their care and stated this made a difference to their overall experience and helped to understand the reasons why particular treatments are prescribed.

Communications

Participants raised issues regarding the quality of communication they experienced within health services, particularly around clarity, consistency of information, and repeated requests for information. Some participants did not understand their treatment and the prescription of particular medications. Information was also found lacking on surgery opening hours, choice of services and treatment options conflicting information from professionals, and lack of information on the status of referrals for specialists and likely waiting times. Whilst participants were generally positive about the interpretation services offered in hospital in other situations it was improvised such as the use of Google Translate.

Retelling of medical issues to different people regarding the same issue was raised in a variety of contexts, the lack of choice or control over the situation leading to additional frustration.

Access to services

Some IT solutions are well received such a text reminder however the one size fits all system of booking appointments for specialists online whilst more efficient for the majority excludes those with low access to IT and low IT literacy or confidence. For these groups the system is prevents equal access and alienates this vulnerable group.

A number of participants indicated they had been provided with information and choice regarding treatment options however due to costs of travel to these options they were not realistic choices and in one case resulted was taken resulting in detriment to both finances and health

Treatment

All participants shared their experience of receiving medical treatment. Positive experiences were reported such as being treated well by doctors in hospital, and the effectiveness of regular check-ups for diabetes and high blood pressure.

However, several participants felt their expectation had not been met; they had not been fully examined, treated effectively or received a specialist referral when they felt this would

have been appropriate. This was particularly prevalent for people who are experiencing pain, mental health issues or unable to pinpoint the problem to the doctor.

We interviewed several participants who discussed differences in the GP's priorities and their own healthcare priorities. Concerns were raised about times when GP's actions contravened a patient's request based on religious beliefs, and the difficulties felt in communicating this to the GP. Similar concerns were raised by patients who felt their treatment was not working. For some knowing the pressure that the NHS is under they were reluctant to take this further and deprioritised their own care needs.

Generally, participants were sceptical about using group consultations for mental health but suggested this approach is better suited for conditions such as diabetes

Overall our findings confirm what we already know about health inequality and highlight the need to recognise that poor experiences, particularly those encountered through the requirement for a 'one size fits all' service may disengage vulnerable people from accessing services they need for their health.

Recommendations

These findings invite service providers to become more aware of the needs of vulnerable people, how to identify vulnerabilities and ensure their own response, including treatment, is responsive to those needs. Specifically, we recommend;

1. Ensuring continuity of health care practitioner for vulnerable people, particularly those with long-term health conditions such mental health and chronic pain;
2. Improvements to the quality of 111 service, so that the first person to answer a call is able to provide accurate clear advice;
3. Consistent language/translation support is provided for people with English as a second language across all services and printed and online information is available in a range of languages;
4. Ensure patients feel that their feedback on NHS services is valued;
5. Provide clear information on service expectations and what options are available if patients feel that these have not been met;
6. Proactively provide and seek opportunities for patients to feedback their experiences in an easy to access and confidential ways that do not require them to read and write;
7. Practitioners trained to prioritise quality, friendliness, equality and respect in their interaction with patients over process and systems;
8. Provide patients with clear accurate information on options available, side effects, alternatives, waiting times and ensure understanding
9. Ensure access and options are appropriate to the patient's ability to engage i.e. IT, phone or travel;
10. Practitioners ensure they takes into consideration the added financial, time and emotional inconveniences that treatment option this might create and adjust options to ensure this is as convenient as possible;
11. Ensure that GP hours are clearly communicated, ideally consistent throughout surgeries, and that surgeries are open long enough to meet the needs of patients in particular areas.

Appendix

1. Quantitative Charts and Graphs

Table 1: Age Questionnaire by cohort and gender. Excluding other and no response. Totals.

Categories	Female	Male
15-24	10	5
25-34	18	17
35-44	34	17
45-54	23	15
55-64	14	15
65-74	6	11
over 75	4	5
Total	109	85

Table 2: Age Clients' database by cohort and gender. Excluding other and no response. Totals.

Categories	Female	Male
15-24	203	164
25-34	644	495
35-44	597	512
45-54	557	516
55-64	419	420
65-74	215	245
over 75	128	153
Total	2763	2505

Table 3: Age Oxford Population by cohort and gender. Totals. Data from Population

Estimates Unit 2016, ONS.

Categories	Female	Male
15-24	18740	19927
25-34	13598	16011
35-44	9296	10156
45-54	8292	8352
55-64	6405	6162
65-74	5092	4666
over 75	5065	3612
Total over 15	66488	68886
Total	79127	82164

Table 4: UK and Non-UK nationality residents. Excluding no response. Totals.

Oxford	Non-UK	43239
	UK	108667
Clients	Non-UK	1566
	UK	2009
Questionnaire	Non-UK	82
	UK	120

Table 5: GP satisfaction - questionnaire participants. Totals.

Scale 1 to 10 satisfaction	Responses
1	12
2	7
3	2
4	5
5	15
6	8
7	18
8	34
9	22
10	55
No answered	25
Grand Total	203

Table 6: Mental Health support satisfaction - questionnaire participants. Totals.

Scale 1 to 10 satisfaction	Responses
1	6
2	2
3	1
4	0
5	4
6	2
7	5
8	4

9	5
10	9
No answered	165
Grand Total	203

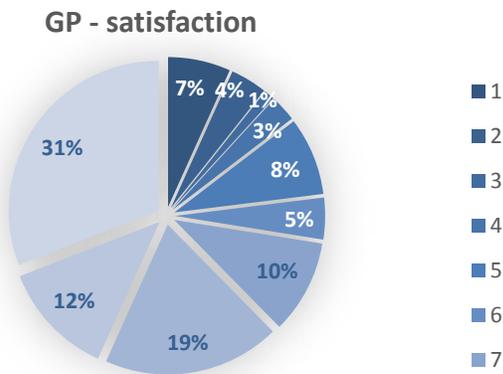


Figure 1: How was your last experience? (scale from 1-10, 1 very negative, 10 very positive) [GP/Doctors surgery]. Percentages. N=178.

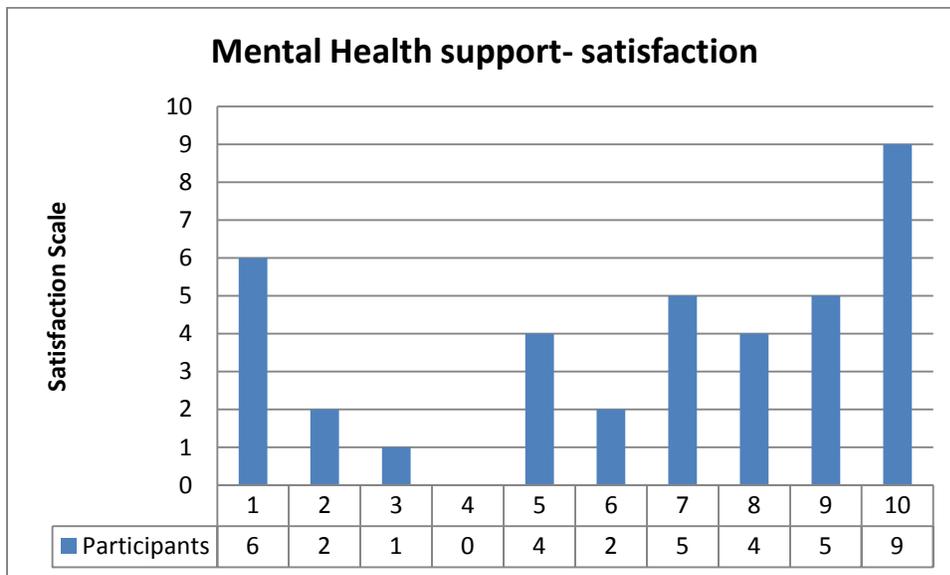


Figure 2: How was your last experience? (scale from 1-10, 1 very negative, 10 very positive) [Mental Health Support]. Totals. N=38.

3. Consent form



Research and Campaigns Client Consent Form

Thank you for agreeing to take part in our research. Before starting we need to make sure that we have your consent.

We have received funding from Healthwatch to research how our clients access health services, and what can be done to improve this access. The information you provide us with in this interview will only be used in this research. All responses are confidential and will be anonymised.

The purpose of this interview is for us to understand the experiences of our clients in relation to health services. We want to know both the good and bad experiences and the reasons to engage or not engage in health services.

At Citizens Advice, we aim to provide the advice people need for the problems they face and improve the policies and practices that affect people's lives through research and campaigning. This is why with this research we aim to understand your experiences so that we can built recommendations and advocate for positive changes.

We can send you access the final report as soon as finished so that you can see the findings and recommendations based on yours and other participant's information. Please write your email address below if you would like us to send it to you

.....

For you to take part in this research we must ask for your consent to use your personal information in our research and campaigns activities. This form is used to do that. However, all the personal information will be anonymous.

Permission to use information anonymously in research and campaigns. I agree to my personal information being used anonymously for Citizens Advice for this research.

Yes / No

Permission to record my voice. I agree to my voice being recorded and used for the purpose of Citizens Advice research and campaigns work.

Yes / No

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