



Have your say

Annual survey
March 2024

healthwatch

Background

At Healthwatch we regularly hear about people's experiences of health and social care. People contact us to tell us what they have liked and also about what might have been better about the care and support they have received.

"Have your say" was devised to allow us to hear the experiences of the people who we are least likely to be contacted by or ordinarily hear from.



Methodology

A set of four very broad questions were devised, giving people the opportunity to comment freely on any service they had recent experience of. Each focused on what was good, what could have been better and how. We also added a specific question about dentistry.

We planned visits to a number of established groups in the community led by a range of providers.

Sessions were planned to engage participants in small group discussions around experiences they were happy to share. Comments relating to each question were to be recorded on flip chart paper.

Consideration was given to possible barriers for each individual group which may impact on expression of comments/experiences, eg language barriers, difficulty in hearing etc.

Methods of delivery were discussed with group leads prior to attendance, to attempt to overcome possible barriers relating to language, disability etc. One-to-one opportunities to maintain dignity and confidence were also to be offered where appropriate.

Vision and Hearing Support supplied some completed paper copies of the survey.

No demographic or identifying information was to be collected.

What we did

The method of collecting data altered as we embarked on the project. We quickly recognised that due to the way many groups were delivered, the group discussion and recording method was not the best fit.

Staff introduced themselves to participants, explained the purpose of the visit and what was hoped to be achieved. Anonymity was explained and people were made aware they could stop sharing information at any point should they wish to.

Participants were made aware no identifying information was being collected and any comments used in our final report would be anonymised.

Questions were both read out and shown (on a laminated sheet) to small groups and verbal explanation given to meanings such as 'health and social care' were given to ensure participants understood the context of the survey. Staff at some groups supported with interpretation.

Questions included:

1. Tell us about your recent experiences of health and social care in South Tyneside?
2. What was good?
3. What could be better and how could it be made better?
4. What are your thoughts/experiences of dental care/oral health?

Responses were recorded on paper by Healthwatch staff on a one-to-one basis within group settings. Participants were reminded about not sharing things they did not wish others to overhear in the group setting. The option to speak more privately was offered for those who chose to feed back to us and was accepted only on a few occasions.

We:

- visited eight organisations
- attended 11 different groups/drop-ins
- spoke with 208 people
- recorded 286 comments.

Ten people we spoke to agreed to be contacted after the group sessions to enable us to support them to gain resolution or to enable their feedback to be noted and forwarded to the relevant agencies i.e. Integrated Care Board (ICB).

Groups we attended and numbers of participants we spoke with are as follows :

Group	Total number of participants spoken to
St Hilda's (drop-in)	20
Apna Ghar	15
South Tyneside Adult Carers (STACS)	35
Naffi Break (Veterans' group)	30
Action Station (drop-in)	15
Happy at Home	50
Big Local	5
South Tyneside Adult Recovery Service (STARS)	7
South Tyneside Asylum seekers and Refugee Church Help (STARCH)	15
Vision & Hearing Support	16
TOTAL	208

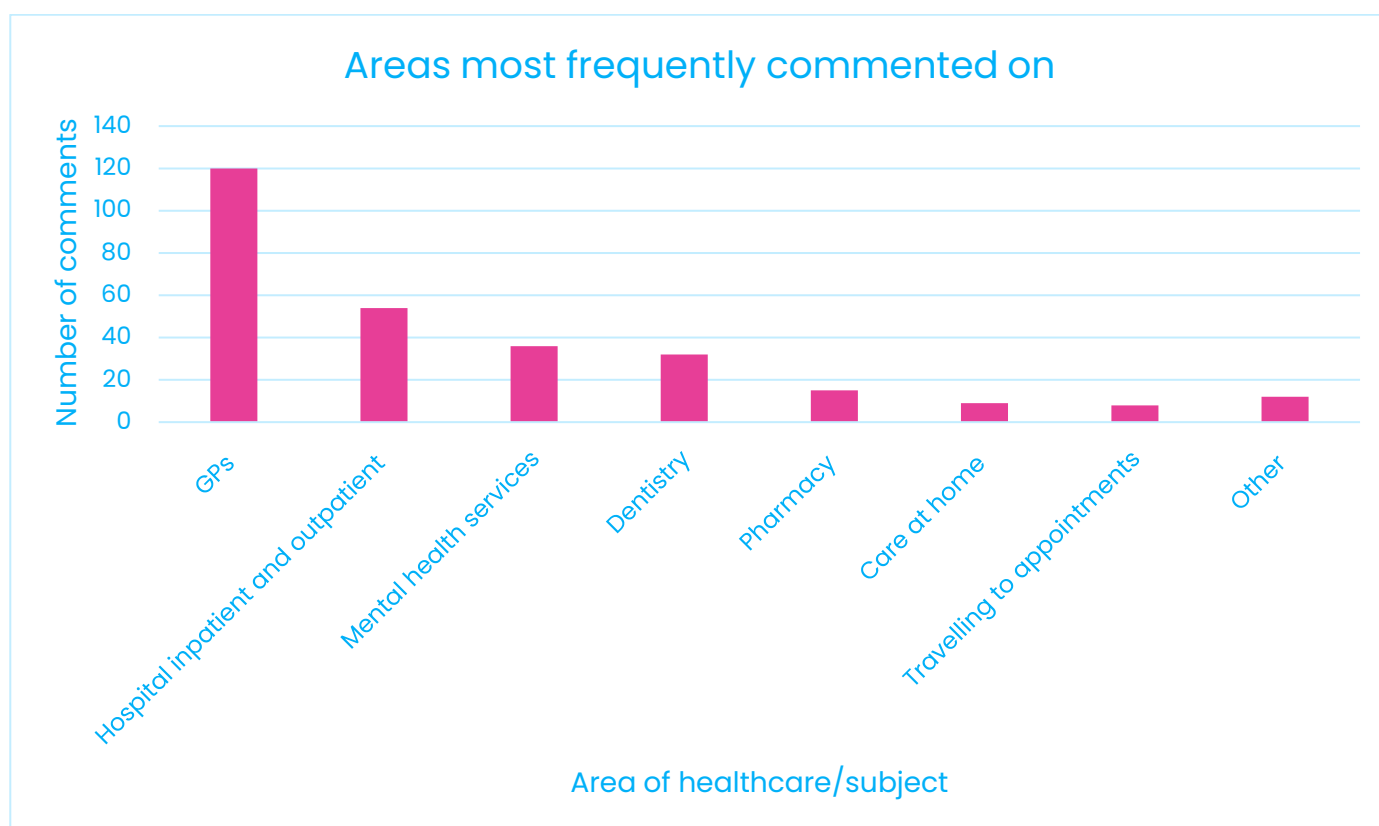
Planned visits which did not take place due to cancellation and difficulty rebooking within timescale of project included:

- New Hope North East
- Humankind
- Alzheimer's Carers Group
- Your Voice Counts
- Age Concern Men's Group
- SURT (Stopping unsafe relationships together).

Findings

Key areas of focus

The key services or subjects raised by participants included GPs, hospital inpatient and outpatient, mental health and dentistry.



Other services highlighted included speech and language, health visiting, leaving prison, transport (including wheelchair taxis/transport and ambulance), opticians, mental healthcare and advocacy, neurology, occupational therapy, district nurses and translation.

Within the seven key areas (and the catch-all 'other' category) themes also became visible as detailed below.

1. General Practice

Experiences of General Practice were by far the most frequent mentioned, with 120 comments made. These were very diverse but the main themes which could be drawn from the data were as follows:

1.1 Getting an appointment

People described the challenges they have around connecting with the surgery to make an appointment:

"Can't get through; 10 people only allowed in queue on phone. I ring from 8am-8.30am for an appointment and often can't get one."

"I want to make diabetes follow up appointment - unable to do - takes so long."

"Don't always have enough credit on my phone to hold on to make an appointment."

"You have to ring at 8.30am or face-to-face at surgery. Once you get appointment it's great - but will only give appointments for that day - can't book."

1.2 Seeing the right person at the right kind of appointment in the best way (including digital/remote methods of access)

People raised frustration around being offered types of appointments which they felt were not appropriate i.e. telephone or eConsult or with someone they perceived was the wrong professional.

"Telephone appointments are no good. Some people can't talk well on the phone."

"I struggle to express myself over the phone. I can't get over to medics what's going on (what's wrong)."

Being unable to use digital methods were also regularly mentioned:

"eConsult very hard to use. Doesn't work for everyone."

"Taking photos of problem not easy to do if you don't understand or have a smart phone."

"To be able to just speak with someone - no eConsult. I just want to know what's going on."

Some patients did see the benefits in eConsult's/phone appointments, however:

"I'm grateful for telephone appointments at GP so I don't have to go all the way to the surgery."

Seeing who they perceived to be the right person was important and people reported having multiple appointments before their problem was resolved:

"Feel like I'm being fobbed off all of the time . Need to see GP but end up with nurse each time have had to go back to see GP."

"Sometimes I just want to see a GP – but they ask you to see Practice Nurse who then decides if you need GP appointment."

"Tried to see GP eConsult – couldn't do so went to A&E who said I'd need to see GP. Couldn't get appointment for three weeks."

"I attended my GP as I had a pain in my leg and wanted something to relieve the pain. The receptionist wouldn't give me an appointment with a doctor. I was offered a physio appointment. Attended one session. It took months for the pain to subside. The receptionist didn't listen."

1.3 Waiting time for appointments

Waiting times were mentioned for GP appointments in addition to being unable to book advance appointments:

"I would have to wait three weeks to see the GP. Able to see the nurse within a week."

"Very long wait times to make appointment – I just go to A&E now."

1.4 Communication

Communication was mentioned several times and within this theme two distinct threads were noted; interpreting service and communication between surgery and patients (particularly reception and follow up appointments/results).

Interpreting/translation services were also mentioned by many people we spoke with, whose first language is not English. Staff supporting people in the community who are

not fluent in English told us how some surgeries go above and beyond in ensuring same day appointments are supported by on demand interpreting services for people but confirmed some surgeries are not utilising this service, meaning same day appointments are not as easily accessed.

One person explained:

“There are no emergency appointments all of the time. I have to go to III A&E.”

“Some ladies are able to use a translation app on their mobiles to get message across.”

“Interpreting for appointments. I take my daughter.”

Challenges already evident and raised previously around GP access are magnified if not fluent/non-English speaking.

“Those with English as second language can’t get around online things.”

“When patients receive a text, they are able to copy and paste to translate. A letter is much more difficult.”

“GPs and hospitals seem to use face-to-face interpreters. This can take longer to book, they may be an inappropriate gender and the patient may know the interpreter which is a bad thing.”

Those requiring interpreting have additional challenges registering or getting an appointment with a GP. Some surgeries no longer complete initial “health check” type appointments for new patients replacing them with a paper form completed outlining medical history/issues. The form is lengthy and direct translation of health issues is difficult on paper.

Communication between patients and surgery

Many comments here were around reception, staff attitudes, sensitivity and not feeling listened to. Some patients did not wish to discuss their health with reception, perhaps not understanding the reason for this:

“Why do we have to give the receptionists health details?”

“Receptionist attitude terrible with those whose English is not good. They just speak louder and very slowly and in broken English.”

“When the results came back, I was told everything was ok. I asked what about the potassium and the receptionist was a bit sharp when she repeated ‘everything was ok’. I wasn’t sharp when I asked the question.”

“Requested repeat prescription at doctors. I told them I was visually impaired and couldn’t do online. They asked me to prove my visual impairment. I should not have to ‘prove’ it.”

Several comments related to people not having results communicated to them or being unsure of what care had been planned including future surgery or appointments:

“I was sent to hospital by my GP for pre-op assessment three weeks ago but haven’t heard anything since. I’ve no idea of when I’m going in, or if I’m going in.”

“I had a bone scan at end of October – still haven’t heard re results.”

“I’m waiting for an operation – I don’t know when or how. No communication.”

Whilst these issues exist, many people who we spoke to spoke very highly of their surgeries and the staff within them. Some told us of the ways staff often went out of their way to support them:

“On the ball. Nurse called to check in on me.”

“My GP kept contacting the hospital to try to bring my appointment closer.”

One person explained how the social prescriber had been:

“Social prescriber been brilliant. “If it hadn’t been for them things would have been a lot harder.”

2. Hospital care

The second most frequent experience area we heard about was hospital care. The themes below reflect the frequencies of comments, with highest frequencies first.

2.1 Good care

This area of focus received the highest number of positive comments in the report around the quality of care and services received:

“Very well looked after when in hospital.”

“Great experience from diagnosis to treatment to recovery cancer services at STDH.”

“Excellent care from paramedics and in hospital.”

2.2 Communication, waiting times and follow up

People talked about how they were contacted by hospitals. A partially sighted gentleman told us about receiving a text to attend a pre-operative appointment when he didn't know was having an operation. His wife asked for all correspondence to be sent in letter form.

Other comments included:

“I had hip replacement over a year ago. I should have had an X-ray one year post-surgery. I was given a telephone appointment. How can they do an X-ray down the phone?”

Staff working with those who are not fluent in English explained:

“Hospital letters/texts are often sent to people who have not had the opportunity to learn to read, or may read in another language.”

Some people indicated worry around awaiting information around upcoming appointments and surgery, results and follow-up from previous appointments:

“Takes a long time to get general neurology appointment for my son.”

“Had swallow assessment weeks ago - was told there was something there, I haven't heard a thing. No results.”

“DR referred me to the hospital for a camera. I still haven't got appointment. The letter states if we need to see you we will be in touch, if you haven't heard by a certain date to call - the issue I have is very serious and embarrassing.”

2.3 Improvements to care

People talked about the care they received. Whilst focusing on specific complaints is outside the scope of the report, some of the comments we received have been documented below.

They reflect what people felt was not of a standard they would expect. Missed opportunities or errors in care were cited by three people.

General comments around basic requirements were noted:

"The ward was filthy – the toilets very dirty."

"I wasn't given a pillow overnight."

"Placement on ward problem – was in with older people with dementia."

"Co-ordination on wards poor – management need to sort this out."

"Patients need to be seen a lot quicker for medical emergencies like heart attacks/strokes."

2.4 Travel/remote clinics/access

Travel to hospitals for care was raised as a barrier to care (see section 7 Travel to appointments):

"Distance issue for appointments."

Problems with parking also featured heavily in comments.

2.5 Discharge care at home aftercare

Problems relating to aftercare on discharge were experienced by some:

"I needed daily nurse visit at home to change an IV. No nurse was available so I had to travel to hospital daily for one week until home visits could be arranged."

"Care in hospital was amazing compared to council care that person got when first discharged. She was so unhappy she paid privately for care at home."

“Home carers when came out of hospital was a disaster. Whilst one carer was here to give person their tea, another carer arrived to put her to bed.”

3. Mental health

Mental health services ranked third most commented on with the following themes in order of frequency.

3.1 Availability of support and therapy

The availability of support in the community was most commented on, with a call for more support within the community and charities for those leaving prison and those using – and in recovery from – using drugs and alcohol.

Mixed comments around access to and waiting times reflected views around therapies and mental health support currently on offer:

“I was told I’d wait 18 months for a CPN.”

“I needed to change my CPN – we just don’t get on but I was told if I did I’d wait up to six months without anyone till someone else was available.”

“I think GPs would rather give pills than refer to Talking Therapies.”

“I borrowed money off family for therapy because I was told I’d be on the waiting list for one year. I needed help there and then.”

“Waited three months for emergency appointment to be seen by MH services. When I got there instead of being seen I was told I would be waiting 12 to 18 months for an appointment.”

“Talking therapies – wasn’t Talking Therapy, they told me what to do, what I should do, need to do, have to do.”

“Alternative therapies should be funded. 90% of illnesses affected by stress.”

One person who felt they needed help said:

“I can’t get back into mental health services. I was classed as non-engaging but that’s because I was struggling.”

3.2 Communication and being able to contact professionals

People voiced feeling stuck when needing to discuss changes to prescriptions or care with the professionals who they were allocated to:

“GP can’t do anything to help with meds as the psychologist has to do this – even my CPN (Community Psychiatric Nurse) can’t and I can’t get to see my psychologist.”

“I can’t get through to CPN if needing something. I have to call Crisis team, wait to speak to someone and then they say they will email the person I need to speak to and get them to call me.”

“I can’t find out when I’ll see my CPN next, she’s been on the sick – there’s no one I can ask.”

“Very poor. I’m just left waiting – no one tells me that I’ll be seen soon or what’s happening.”

Two people mentioned sharing mental health care:

“Services are very disjointed and don’t talk to each other.”

“GPs should have power to sort out meds and co-ordinate some mental health service.”

3.3 Crisis team

The Crisis team received mixed comments:

“Crisis team have been amazing with me – very good.”

“Service doesn’t meet needs of my daughter (Initial response team not acting on things suicidal and self-harming).”

“Gap between being in crisis and needing help. People have to get to breaking point before they will be helped. Early access would prevent a lot of the crisis that’s going on.”

One person said:

“Crisis team (the name of the team) is misleading – they don’t see people in crisis.”

4. Dentistry

Dentistry has been a topic of concern for many people. The following themes emerged whilst speaking with people who we spoke to. Surprisingly there were not as many comments around dentistry as other key areas. Knowing where to go if they had a dental emergency was discussed in group settings but did not feature much in comments.

4.1 Positive feedback

The most frequent theme in this key area was positive feedback. Many people told us that they had a dentist whom they saw for regular check-ups.

Some people praised their dentists who they felt accommodated specific need, such as being seen in a ground floor room and completing home visits:

“Made facilities for me as I can’t get upstairs.”

Many people simply stated:

“No problems.”

4.2 Registering

Registration at a dentist was the second most frequent theme. People told us they could not register to be seen at practices in the area for NHS care or were told they were no longer eligible to book appointments at the practices they were usually seen at as they had not been seen for some time:

“Not registered anymore.”

“Can’t register.”

“They won’t see NHS patients – they tell me I have to go on waiting list. I have a broken tooth and was on list five to six months.”

Some people believed their language barrier prevented their registration:

“Two years in the UK and not registered with a dentist.”

Families told us they could not register the whole family:

“Kids are registered – I don’t know where to go for treatment – I need a filling.”

“My children are registered but not myself and my husband.”

4.3 Care received

People told us about the way that practices responded, managed expectations, including waiting times and possible cost.

“Receptionists need to show compassion.”

“I was asked to book a six month appointment when I went downstairs to reception they said “they didn’t have any for nine months!”

“I had to wait three months for a denture – in the end I just had to pay £400 for it as I couldn’t wait.”

“No problems registering but after being told it was free care I received a bill for £100.”

“Waited a year for a denture.”

“Informed that if son’s retainer broke then the parent would have to pay for a new one. Son had a seizure and parent had to pay £92.”

4.4 What could have been better

People talked about what could have been better. Whilst focusing on specific complaints is outside the scope of the report most comments were around problems with ill-fitting dentures, lack of continuity of care and some issues which took place during lockdown in 2020 and have only been recently resolved.

5. Pharmacy

Poor service was talked about by people in relation to their pharmacy contact. Most common comments heard were around frustration with getting prescribed medicines (from ordering to receiving).

5.1 Getting medications

“Gets meds in blister packs. Was refused. Told to go to another pharmacy.”

“Through patient access you wait 24hrs for a repeat prescription. I could wait a week-and-a-half for all my meds. Moved pharmacy and now get much better service.”

“Pharmacy often give prescription late, sometimes give half prescription and I need to collect the rest (they owe you) and sometimes give cheaper alternatives of meds.”

“Encouraged to order prescriptions online. No use if you don't have a computer.”

5.2 Medical support at the pharmacy

Encouragement to utilise pharmacies for medical needs was mentioned:

“GP sent me to pharmacy for ears. They told me there was wax. Told me I'd have to pay £10 for them just to look. When I said I'd go back to GP pharmacist told me I'd be on a long waiting list. I went back to GP and had ears sorted in two weeks. The pharmacy were going to charge me £40 to do it.”

Privacy and the busy nature of pharmacies was also mentioned:

“Pharmacy is time – very crowded, too many other people standing about.”

5.3 Good service

Some people praised their pharmacies, particularly around delivery:

“My pharmacy worked with my GP to reduce my morphine prescription. I no longer take it.”

“Prescription delivery is great.”

“Deliveries very good.”

“Service not bad but meds can take a long time.”

6. Care at home

This topic received a few comments which mostly described mismatches between expectations of care and care provided.

6.1 Care provision in the home

Family members/carers for others described their experiences and sometimes frustrations when dealing with carers and care companies. Many comments centre on communication, completing tasks which were part of the person’s daily care (and care plan) and around hygiene. It is not within the scope of the report to explore these complaints.

One person told us about a carer sent in to help with meals who couldn’t make a salad. They followed on to tell us how the care company kept trying to send new staff with no experience.

Some people told us they were happy with the care their loved one received:

“Carers great, four visits a day to help with meals, meds , shower etc.”

6.2 Residential care

One person told us that due to low staff levels they missed an important hospital appointment. They believed that this resulted in their having to have an operation as the next appointment was re-booked for months later.

7. Travel to appointments

People talked about their experiences of traveling long distances on public transport to appointments with services that are not available in their locality. This key theme threaded throughout other sections of the report (primarily section 2 Hospital care):

“Access to RVI is ok. Newcastle General is difficult for access.”

“I have to go to the QE for some care but there are no busses. I can get to the RVI

easier. Its £40 for a taxi to get me to QE, need more local services.”

This person spoke about the difficulty they had accessing speech and language services due to geographical distance and reliance on public transport:

“Speech and language services centralised to Sunderland – I can’t get to the out-of-school groups for my child. The times are too close to school, I can’t take my other child and don’t have childcare. The distance is hard, the bus will take a long time – we will always be late.”

A person whose partner was a wheelchair user told us how she struggled at times to get the wheelchair onto local buses, meaning she often relied on taxis:

“Wheelchair taxis expensive and like gold dust.”

Another person told us:

“Can’t get taxi from the house. Disabled taxis are busy due to children’s school drop-off times.”

Many people praised ambulance and paramedic services:

“Ambulance service excellent very good care.”

“Ambulance service picks me up and takes me to Freeman. I ring up and they are always on time.”

“I had a fall, I was stuck on my knees for 2hrs. Paramedics couldn’t lift me so had to request a special chair. Excellent care from paramedics and in hospital.”

8. Other areas

We heard some comments which were not so frequent that we felt they required their own section in the report.

Occupational therapy/physiotherapy

“I needed mobility aids – they were great. I had a good assessment.”

The staff lead at one of the groups we visited told us:

“South Tyneside Council, Occupational Therapy and Keelman’s Way are excellent. Gone over and above. Following our contact transport was put in place for one disabled child and a bath seat put in place for an older service user.”

Health visiting service

Staff at a group we visited told us:

“Health visitors sometimes are not informed that the family they are visiting have no English. Health visitors are very proactive in arranging interpreting for these families.”

Other comments

Some people we spoke to highlighted the difficulties they had leaving prison:

“Continuation of healthcare when in and leave prison.”

“Need ID to get a GP when come out of prison.”

District nurses

“Can’t get through to district nurses – phone just rings and rings . I tried nine times yesterday at different times of day.

Opticians

“I went as glasses were wonky – they realised they weren’t right so adjusted. They wanted to test my eyes again. They were done a few weeks ago. They wanted to charge me again. I didn’t let them.

111 service

This was mentioned in relation to non-English speakers:

“The 111 service asks a lot of press button questions before it asks if you need an interpreter. No use if you cannot understand the questions.”

Key observations

Communication

We heard a lot of comments about communication relating to different services.

People felt communication of information from GPs, hospitals and mental health services around results of investigations, what care is planned for them and information around wait times was lacking.

People tended to praise staff/services when they felt they were supported to understand the care they were to receive or things were explained to them.

Interpreting services appear not to be being utilised within general practice and (not so much) in the hospital. Information from GPs and hospitals is often in a format that can make interpreting letters/texts/appointments etc. difficult.

People told us how within mental health services communication (actually getting in touch with) with key staff around care was a challenge.

General Practice

Getting the right type of appointment type with the right person at GP surgeries continues to be a challenge for people. A reliance on eConsult to triage people appears to make them feel not listened to and frustrated particularly when they can't see the professional they feel they need to and have several appointments about the same issue.

Hospital care

This was related to positively by many people but perceived improvements to care by those experiencing it exist.

Travel

Travel to appointments particularly specialist clinics can be problematic especially if relying on public transport and in relation to cost if a taxi is required. Magnified further if person requires adaptations to enable them to travel.

Mental Health

Availability of support (including crisis) and therapies seemed key in this area.

Dentistry

Those lucky enough to be registered already were positive about services. However families struggled to register at the same practice and wait times and explanation of possible costs of some care left some people feeling very frustrated.

Pharmacy

Difficulty ordering and receiving prescribed medications in a way that suits the patient persists. Care in pharmacies had mixed reviews but privacy was mentioned as a factor especially as pharmacies become busier with increased footfall.

Care

The key finding was the reported mismatch between the care the person required and what was given.

Recommendations

Communication

- Consider methods to better communicate information around results of investigations and planned care with patients.
- Greater use of interpreting services – perhaps increasing awareness with staff in GP practices around what is possible within the services they have at their disposal.
- Care around ensuring information is in a format that can be understood and easily translated (where appropriate).
- Consider new ways in which recipients of mental health support might contact staff who are responsible for their care to enable them to raise their concerns.

General Practice

- Patients need to feel that they are receiving the best service from all staff at their GP practice. There needs to be better communication, especially around test results.

Travel

- Consideration given to the location that a patient is being asked to travel to for tests; some patients do not have the means to cover the cost of a taxi.

Mental health

- Greater communication of the availability of support (including Crisis) and therapies in the community, including those in the VCSE sector, may enable people to access support on their doorsteps which may support them whilst awaiting allocation of CPN or other therapeutic interventions.

Dentistry

- Clear upfront explanation of costs should care be completed privately. Family approach to registration might enable whole families to be looked after at one surgery.

Pharmacy



- Consideration of where consultation takes place may alleviate worries about privacy. Consistency around what pharmacies can/will/do provide as their offer to the community.

We'd like to thank all the organisations and individuals who assisted us with this report. The findings and our recommendations will be shared with health and social care commissioners to assist future service planning.



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