healthwatch Devon



Quarterly Intelligence Report: People's experiences of health and social care services in Devon

April - June 2017



People's experiences of health and social care services in Devon

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About Healthwatch Devon

Healthwatch Devon is the independent health and social care champion for people. We exist to make sure that people are at the heart of care. We listen to what people like about services and what could be improved. We share their views with those with the power to make change happen. We also help people find the information they need about services in their area.

In summary - Healthwatch is here to:

- Help people find out about local care.
- Listen to what people think of services.
- Help improve the quality of services by letting those running services and the government know what people want from care.
- Encourage people running services to involve people in changes to care.

About this report

Since Healthwatch Devon was introduced in 2013, thousands of people have shared their views and experiences with us in relation to their local health and social care services.

During the period 01 April - 30 June 2017, we engaged with more than **1,450** people. This engagement was through our consumer champion work, our events, and activities and through our project works and surveys.

Included in this figure is the **77** people who used our feedback form to have their say and share their experiences. The information on the following pages is a summary of these patient stories that have been shared with Healthwatch Devon. The report does not include recommendations but is based on **unprompted feedback** from Devon residents and is intended to make the views of local people known to managers of health and care services and make them aware of the things that matter to patients, their friends, family, and carers.

citizens advice

The information about the advice line calls, of which there were **300** during this quarter, are provided by Citizens Advice, our delivery partner who run this service. They deal with specialist queries and case referrals and have provided the case studies.

Intended audience

- Relevant commissioners and providers of services referred to in this report.
- People who use health and social care services, their friends, family, and carers.

This report has been prepared in accordance with section 221 of the Local Government and Public Involvement in Health Act 2007. We invite comment and response from commissioners, providers, and local care organisations. As a result, this will help to create constructive dialogue. We thank those providers who have responded to the report. You can find their responses on page 32.



Healthwatch champions

Our Healthwatch champions are provided by Citizens Advice, our delivery partner who run this service and provide advice and support about health and social care services. As well as face to face support they provide an advice line service Monday - Thursday 10:00am - 4:00pm.



The Healthwatch Champion deal with specialist queries and case referrals can advise and support with:

- What to expect from health and care services.
- Who should be paying for what.
- Complaints and support with making complaints.
- Signposting to local services.

Themes in relation to advice line calls

The information about the advice line calls, of which there were **300** during this quarter, are provided by Citizens Advice. These were the tops themes of the calls dealt with for each area.





Nature of the feedback provided

The following shows the comments recorded broken down by the nature of the experience.











Request for Information

What people are commenting on

The following shows the types of services that were commented on (using our have your say feedback form) and how the person felt about their experience.





Hospital services

The following are the views regarding hospital services including secondary and community care and emergency services and the ward or department where the experience took place. The tables also show the sentiment expressed by the person explaining how they felt about their experience and the theme(s) relating to the feedback. See appendix 1 for more information on themes

Northern Devon Healthcare NHS Trust manages acute services from North Devon District Hospital, 7 community hospitals as well as community services across northern Devon.

| Hospital or service | Ward or department | Comment sentiment* | Themes relating to the feedback |
|----------------------------------|-----------------------------|-----------------------|--|
| North Devon District Hospital | Ambulance Services | Positive | Quality of Treatment, Staff attitudes |
| | Accident & Emergency | Negative | Choice, Dignity |
| | Ophthalmology | Positive | Access to Hospital Services, Quality of Treatment, Staff attitudes, Waiting Times |
| | Glossop Ward, Acute Care | Negative | Discharge, Waiting Times |

Plymouth Hospitals NHS Trust provide services for patients at the following main sites Derriford Hospital (which has more than 900 beds, Plymouth Dialysis Unit, Child Development Centre as well as through clinics provided at other local hospitals and care centres.

| Hospital or service | Ward or department | Comment sentiment* | Themes relating to the feedback |
|---------------------|-----------------------|-----------------------|--|
| Derriford Hospital | Orthopaedics | Negative | Safety, Staff attitudes, Waiting Times |

Royal Devon and Exeter NHS Foundation Trust have over 800 beds at the Wonford and Heavitree hospital sites in Exeter. It also provides patient care managing the day case surgery activity in Devon community hospital theatres, community midwifery services, stroke care, renal dialysis units, as well as the specialist care eye clinic.

| Hospital or service | Ward or department | Comment sentiment* | Themes relating to the feedback | |
|-----------------------------------|------------------------|-----------------------|--|--|
| Axminster | Outpatients | Positive | Quality of Treatment, Staff attitudes, Waiting Times | |
| Community Hospital | Inpatient Care | Mixed | Procurement / Commissioning | |
| Craditan Haspital | Outpatients | Positive | Quality of Treatment, Staff attitudes | |
| Crediton Hospital | Outpatients | Positive | Quality of Treatment, Staff attitudes | |
| Heavitree Hospital | Other Negative | | Appointments | |
| Ottery St Mary Hospital | Outpatients | Positive | Quality of Treatment, Staff attitudes | |
| Sidmouth Minor Injuries Unit | Minor Injuries Unit | Positive | Quality of Treatment, Staff attitudes | |
| Tiverton and District Hospital | Inpatient Care | Negative | Access to Hospital Services, Referral, Waiting Times | |



| Hospital or service | Ward or department | Comment sentiment* | Themes relating to the feedback |
|---|-----------------------|-----------------------|--|
| | Radiography | Negative | Appointments |
| | Radiography | Neutral | Access to Hospital Services |
| | Cancer Services | Neutral | Quality of Treatment, Staff attitudes |
| Royal Devon & Exeter Hospital (Wonford) | Cardiology | Mixed | Access to Hospital Services, Appointments, Consultation |
| | Kenn Ward | Negative | Consultation, Discharge, Quality of Treatment, Safety, Staff attitudes |
| | Inpatient Care | Negative | Access to Hospital Services, Referral, Waiting Times |
| | Other | Negative | Fees / Charges, Quality of Treatment, Staff attitudes |

Royal Devon and Exeter NHS Foundation Trust continued....

Torbay and South Devon NHS Foundation Trust is an integrated organisation providing acute health care services from Torbay Hospital, 9 community hospitals as well as community health services and adult social care.

| Hospital or service | Ward or department | Comment sentiment* | Themes relating to the feedback |
|---------------------------------------|-----------------------|-----------------------|--|
| Dartmouth Clinic | Outpatients | Positive | Quality of Treatment |
| Newton Abbot Community Hospital | Outpatients | Positive | Staff attitudes |
| Teignmouth Community | 0.1 | Positive | Quality of Treatment, Staff attitudes |
| Hospital | Outpatients | Positive | Staff attitudes |
| Tarkay Haanital | Inpatient Care | Negative | Access to Hospital Services, Waiting Times |
| Torbay Hospital | Other | Negative | Access to Hospital Services, Referral, Waiting Times |

South Western Ambulance Service NHS Foundation Trust has responsibility for the provision of ambulance services across the counties of Cornwall and the Isles of Scilly, Devon, Dorset, Somerset, Wiltshire, Gloucestershire and the former Avon area. Core operations in Devon include emergency ambulance 999 services (A&E).

| Hospital or service | Comment sentiment* | Themes relating to the feedback |
|---------------------|-----------------------|--|
| Ambulance Services | Negative | Access to Hospital Services, Waiting Times |

Budleigh Salterton and District Hospiscare provide specialist palliative care advice to patients who have been diagnosed with a chronic life limiting condition.

| Hospital or service | Comment sentiment* | Themes relating to the feedback | |
|--|-----------------------|---------------------------------|--|
| Budleigh Salterton & District Hospiscare | Negative | Dignity | |

*NB the comment sentiment column in these tables do not reflect an overall service rating but is rather a categorisation of the nature of the views given on a particular theme.



Themes in relation to hospital services

When Healthwatch Devon records patient feedback, the experience is categorised in to themes. Depending on how much information is provided, feedback can refer to more than one of these themes. The following are the top 5 themes in relation to hospital services.

Confidentiality Access to Hospital Services Records Management Staff Attitudes Appointments Waiting Times Quality of treatment Discharge Safety Monitoring & Accountability Diagnosis

We found that a quarter of the feedback received was given a theme of **staff attitudes**. Most of the experiences with this theme were positive. Comments included helpful nurses, efficient service from friendly staff and courteous and professional service. However, we did also hear about staff "openly, within hearing distance of patients, sharing negative attitudes that should be left in the staff room."

I had been working in the garden when I felt very dizzy and had chest pain. I dialled 999 and an ambulance attended. The two paramedics were excellent, remaining professional, whilst putting me at ease. The treatment at Barnstaple hospital was as good as you could expect. Tests, attention, and information; on a Saturday evening when it was busy. I say well done to everyone. I had an appointment at the community hospital and found the service excellent. The staff were friendly, efficient, and explained the procedure before the examination. The result was good and was fully explained and I was reassured and happy. I would rate this service as excellent and would be extremely likely to recommend to my family and friends.

Three quarters of the comments relating to quality of treatment were positive. People expressed being happy with the information they were provided regarding treatment and that they felt reassured by the service that was offered. Although quality of treatment around discharge was negative.

75% of the stories regarding **waiting times** were negative. Some of the issues are regarding waiting times for referrals as well as waiting times during the discharge process.

I have now been waiting for 21 weeks for my operation. My bag has been packed since my pre-admission appointment. Still waiting for a date. I was told 2 weeks ago it will probably be another 12 months.



Referred for assessment to chronic fatigue service but referral was lost. Re-referred but still I'm waiting a home visit. I have been waiting for over 6 months which leaves me feeling depressed and no further forward. I am exhausted trying to battle the health system. Just over half of the patient stories with the theme **access to hospital services** were negative with issues of accessing hospital services being problems with referrals and waiting times.

Two thirds of the feedback regarding the theme of **appointments** was negative. The experiences shared included mistakes in dates and times given in appointment letters meaning wasted trips.

Appointment was at 2.30pm however patient was not seen until 5.30pm. It takes an hour each way for travel and the lady, when under stress like this, was very sick on the return journey.

Case study provided by Citizens Advice in relation to hospital services



Edie told us how her long wait for surgery left her feeling isolated and lonely.

Edie had been waiting for a bowel operation, the 8 months wait meant her health had deteriorated, leaving her in severe discomfort and pain. She had become mildly incontinent and this left her fearful to leave home. She was feeling isolated and lonely.

Edie had already tried on several occasions to get an appointment with her consultant, but was consistently informed that there were long waiting times and nothing could be done to speed up a date for surgery. Her GP had tried to intervene, but this was also met with the same response, with no indication of when surgery would commence.

We helped Edie write a letter of complaint to the hospital, asking for an immediate date for surgery which was sent to the PALS Team.

As a result, a date for surgery was set for the following week. Edie was put in touch with a local voluntary organisation that runs transport to and from the hospital, as neither she nor her son could drive.

Edie was delighted to finally get the operation she needed and has since made a full recovery and said that her aftercare treatment has been great.





Experiences shared in relation to hospital services

The following are the patient stories that have been shared with us during the last quarter. These stories are sometimes shared by the individual receiving the care, a friend or relative or sometimes reported by an advocate who is providing support.

- 1. Several years ago my husband and I went to our GP who witnessed our signatures and recorded on the computer system that neither one of us wished to be resuscitated. However, last year my husband had a fall and was unconscious, an ambulance was called and he was admitted to hospital. The A&E department at the hospital would not accept our Do Not Resuscitate wishes because my husband was not carrying a certificate. My husband died a month later, having endured little quality of life during his final weeks. We thought we had done everything necessary to ensure us a dignified peaceful death. We did not know about Treatment Escalation Plan, we are not computer literate and I feel like I failed him. My husband was well cared for and I was there when he died, but the last month should not have happened. Quality of life should be the deciding factor the my husband lost all quality.
- 2. My wife had leukaemia diagnosed in her early sixties, she was treated at the haematology unit at the RD&E for eight years. They stopped her chemotherapy and the bloods to see if the body would start healing itself. She did have a hip and knee replacement in 2012, whilst in the RD&E she had a stroke and was then discharged home so I could look after her until she died. While she was at home our GP called in 2 or 3 times a day. I did have night care from Macmillans and they also helped with washing my wife.
- 3. I went into the North Devon District Hospital for my cataract operation. Waited around for 6 hours in total. The staff were very nice and polite. Offered me lots of tea. Operation went well and I was very happy with the service I received. I just hope they don't close this unit down because people like me cannot travel to Exeter for an operation.
- 4. Went for a scan at local hospital and found the experience from the staff helpful and reassuring. The ultrasound scan was something new to me, it was nothing to get concerned about or worry about. I have rated this service as an excellent 5-star and would be extremely likely to recommend to family or friends.
- 5. Individual feels that if their elderly friends had been treated locally, at their community hospital or Seaton community hospital, which is about 8 miles away, instead of having to take the long journey into the RD&E for their treatment they may still be here today.
- 6. Went for a scan at the community hospital and found the service provider fast, friendly, and efficient. I would rate this service as an excellent 5-star rating and would be extremely likely to recommend to family or friends.
- 7. Person had a letter which said they had an appointment on bank holiday Monday at 19.00. Community transport group managed to find a kind volunteer driver to take them but when they arrived they were told that the letter mistakenly had this date and in fact the appointment was the following day so the driver had wasted their evening.

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- 8. Early in 2016 I visited my GP with increasing pain in both knees. A referral was made to x-ray department and I was told by the consultant that both knees needed total replacement and the operation for the left knee was scheduled for summer 2016. In the meantime, whilst recovering from my operation my prostate condition reappeared and I started having hormone therapy a month later. This meant that the Peninsula Hospital, where I had my left knee replaced would not carried out the right knee replacement operation as their contract stated patients that are undergoing additional therapy for an unrelated medical condition with the NHS cannot be patients for major surgery. I was also refused at the Nuffield Hospital under the same clause of their contract. The orthopaedic surgeon checked the waiting list for Derriford orthopaedic operations and I was told 5 months wait. However, I was put on the urgent/cancellation list and a space came up late 2016. The morning after my operation I woke up and desperately needed the toilet, whilst sitting on the toilet I fell and smashed my kneecap of the previously totally replaced knee 6 months earlier. Due to the fall, the x-ray showed I have fractured my patella and so my left knee needed an immediate operation. Nine days later with both knees repairing I was transported to the South Hams (Kingsbridge) Community Hospital. After 4 weeks rehab at South Hams Hospital I went home to recuperate and my progress has been positive. The NHS ethos that the service should be patient led leaves a lot to be desired. My lasting impression of the Derriford hospital staff is that they are there to chat amongst themselves openly within hearing distance of patients on subjects such as agency staff rates of pay, their own personal problems, sharing negative attitudes that should be left in the staff room.
- 9. Went for my aorta check at community Hospital. I found the service provider courteous and professional. I would rate this service as excellent 5 stars and extremely likely to recommend to family or friends.
- 10. Went for a scan and found the experience quick, efficient and friendly. They have rated this service as an excellent 5-star rating and would be extremely likely to recommend to family or friends.
- 11. Persons 16-year-old daughter fell from her horse and suffered a double fractured leg. It took the South-Western Ambulance crew 1 hour and 25 minutes to attend the scene. Parent is furious and has made a complaint to SWAST and CQC for a full investigation.
- 12. Person presented his employment and support allowance certificate and evidence of low income to an admin officer at the RD&E to claim back travel costs. The officer crossed out 12 months valid and amended to 6 months. They were not asked what other benefits they were on. Person is upset that the officer amended the paperwork and wanted to know could they do this. They did not check fully the circumstances or give them an opportunity to correct missing paperwork or give further advice on how to claim back.
- 13. Individual had an appointment at community hospital and found the service provider excellent. The staff were friendly, efficient and explained the procedure before the examination. The result was good and was fully explained and I was reassured and happy. This individual has rated this service as an excellent 5-star rating and is extremely likely to recommend to family or friends.

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14. The individual was rushed into hospital by ambulance having suffered a heart attack and a stent was fitted. Whilst in hospital they talked about the patient going for a MRI scan to check that the blockage was now clear. However, they were given the wrong information and a MRI scan was not organised and they were discharged to go home. This resulted in the individual having to arrange a MRI scan themselves, they were informed that they would have to wait 14 weeks for the scan. Prior to the scan a nurse informed them that both arteries were over 50% blocked. The individual feels that it would have been helpful to have been able to discuss their condition and treatment with the consultant at the RD&E hospital. The GP was provided with a condition and treatment summary however, they found the language and technical jargon on this summary extremely confusing. The GP has told them to just keep taking the tablets. Historically this person has had family members suffer from a heart attack and subsequently die. They are very worried about their future as they have a progressive disease. The individual has taken steps to a healthier lifestyle since the heart attack, losing weight, eating, and drinking healthier and has taken up daily exercise. Despite the healthier lifestyle the hospital has informed them they are still at a greater risk of further heart attacks because

of the inherited condition from both parents. They are very concerned that they are waiting for, rather than avoiding, further heart attacks. They are aware that there are numerous medical conditions that have preventative medical interventions tests and scans etc. however, they haven't been offered any tests, checks or scans annually or in the next two to three years. They have found it difficult that they did not receive a follow up appointment with the consultant, they have been told there is no money for these type of appointment checks. Whilst in hospital it was concerning that some of the other patients were back in hospital having suffered a second or third heart attack.



15. Clients husband discharged from hospital to nursing home with a defibrillator. Cancer present and health got worse so was taken from nursing home to hospice. Husband's support was withdrawn and allowed to die, however defibrillator kept restarting so client was brought back several times. Client felt that no one was taking any notice about defibrillator and that she was imagining it. Eventually husband took 9 days to die. Hospice held a meeting and gave out advice to all nursing homes in this situation to 'switch' off the defibrillator, advise that one is fitted, it has magnets to locate if one is fitted. Client has yet to receive a formal written apology and is also concerned that the Hospitals are not included in the advice from hospice. They are is still deeply traumatised from watching events from 2 years ago and needs closure.



- 16. Husband was admitted to hospital after a fall. He suffers from dementia. When due for discharge, he was not assessed prior to discharge regarding his ongoing care. Wife was told by staff on the ward that he was perfectly capable of looking after himself and he was going home. The wife has a serious long-term health condition and is unable to provide care, the staff on the ward were advised of this. Husband was discharged home, but left with no care for 2 days, during which time he had no medication or meals.
- 17. The individual found the service provider very good, very polite people and they told them everything. They have rated this service as an excellent 5-star rating and would be extremely likely to recommend to family or friends.
- 18. My GP referred me for a total hip replacement in May 2016. I fully expected to receive a letter from the hospital but instead the surgery contacted me to say that the referral had been returned to them because there was not enough detail on the paperwork. I gather that this is far from unusual and stems from the North, East and West Devon CCG. I received a letter asking me to telephone Devon Support Services. I called as soon as I received the letter and spoke to someone who asked me to confirm that I still needed the operation. When I assured them that I most certainly did they assured me they would progress the referral. I said I was not happy about the process and they gave me the details of the PALS service. I contacted them and they suggested I complete the DRSS online patient survey to see if they could help. I did so and received a reply which explained that the referral was returned to my GP as my referral letter did not say if I had already had physiotherapy. The referral was therefore returned for my GP to confirm that I had received physiotherapy. If not I should be referred for physio as the guidelines for my condition, as described by my GP, state they should refer me. This reply was basically a disclaimer and continued - Your referral has taken longer to process than is preferable but we have followed the agreed guidelines for orthopaedic patients in Devon. That may be the case but it is hardly an efficient use of resources and reveals an appalling misuse of NHS funds. I did finally receive an appointment 2 month later at Tiverton Hospital. I saw a different member of the team who took me through the same examination as had my GP and confirmed that I did indeed need a hip replacement. They immediately put me on the waiting list for the operation at RD&E. I received a letter from RD&E confirming that I had been added to the waiting list and a second letter asking me to confirm that I still required surgery, which I did, and saying that at most it will be within 6 months. That would have brought us to January. Alas, I am still waiting, 11 months since my GP first referred me. I have lost count of the number of times I have telephoned the hospital. I have written to my MP and received a rather negative reply! I also contacted the PALS service at the RD&E but they were not able to help beyond suggesting I contact the PALS service of the CCG. I seem to be going around in circles and am still no nearer to having surgery on what is an increasingly painful and debilitating hip. To add to my problems, I had to defer the operation because I am taking exams in May and June. I have asked for my name to be put back onto the active waiting list for a date following as soon as possible after my final exam but when I phoned the hospital they could not tell me where I was on the list and explained that they were trying to contact that day's elective patients to cancel their operations as they had had a large number of emergency admissions. Obviously, the cancellations will have to be re-booked and so on and on.



- 19. Person requested a referral to Guys Hospital but was refused. They complained and this decision was eventually reversed, but they are unhappy with the wording in the reply. Even though the service apologised for "the incorrect interpretation of the referral rules", the client feels the rest of the letter tries to blame them for wanting "a third opinion". This is just not true. Client has been discharged from hospital for previous back problems, this referral was to continue the heart treatment they have been receiving at Guys for many years.
- 20. Went for a scan at the local hospital. The person found the service provider excellent, efficient, charming, and reassuring. The staff welcomed the individual at the reception and were professional through to their screening. They did not think anything needed to be improved and that we in the UK are very lucky to have the NHS. They have rated this service as an excellent 5-star rating and would be extremely likely to recommend to family or friends.
- 21. I recently had my chest x-ray to check for any symptoms of TB as I had recently been in contact with family members who does have TB and the x-ray showed a negative result. All clear for TB, I just had a cold.
- 22. My husband was recently an inpatient in hospital for 10 days. On the day before he went home he was told that he would be going home tomorrow. Just before lunch on the following day he was told he could go home and just needed to wait for his medication and verification of some follow up treatment. The doctor dealing with the verification could not get hold of the appropriate people to arrange this so we were asked to wait. Mid-afternoon a member of staff gave us my husband's medication. Half an hour later the doctor returned to informed us that the treatment verification still needed to be arranged and they were going to send the details in a letter to my husband. Our main concern is about that my husband was blocking a bed for 4 hours. My husband and I have had experiences waiting in A&E for a bed to become available, which is extremely distressing and uncomfortable. It all seemed very unnecessary, to keep us waiting all that time was stressful and we had a long way to go home. I understand from talking to others that this is not rare and waiting times can be a lot longer, what is going wrong?



23. Fantastic service. Nurses were so helpful.



Social care services

The following are the views regarding social care services including residential and nursing care homes, carers services and children services. The table also shows the sentiment expressed by the person explaining how they felt about their experience and the theme(s) relating to the feedback. See appendix 1 for more information on themes.

| Service provider | Service or department | Comment sentiment* | Themes relating to the feedback | |
|---|---|-----------------------|--|--|
| Barton Place Nursing & Residential Home | Residential Care Home | Negative | Cleanliness, Dignity, Fees / Charges, Quality of Treatment | |
| | Assessment | Negative | Staff attitudes, Waiting Times | |
| | Assisted Living | Neutral | Access to Social Care Services | |
| Care Direct Devon | Care Assessments | Negative | Access to Social Care Services, Fees / Charges, Referral, Waiting Times | |
| | | Negative | Access to Social Care Services, Choice | |
| | Carers Services | Neutral | Service Coordination | |
| | Children Services | Negative | Access to Social Care Services | |
| | Children Services | Negative | Consultation | |
| Devon County Council | General social care services for adults with a physical disability | Mixed | Access to Social Care Services | |
| | Residential Care Home | Neutral | Access to Information | |
| NEW Devon CCG | Continuing Health Care | Negative | Fees / Charges | |
| Riverview Care Home | Nursing Care Home | Negative | Access to Social Care Services, Nutrition & Hydration | |
| The Come Commonly | | Negative | Fees / Charges | |
| The Care Company (SW) Limited | Care at Home | Negative | Choice, Fees/Charges, Suitability of Provider/Staff | |
| The Integrated Care Clinics | | | Access to Social Care Services, Choice | |
| Torbay and South Devon NHS Foundation Trust | General social care services for adults with a learning difficulty | Negative | Access to Social Care Services, Quality of Treatment | |
| Toundation must | Nursing Care Home | Neutral | Access to Social Care Services, Nutrition & Hydration | |
| Venn House | Residential Care Home | Mixed | Cleanliness, Safety, Suitability of Provider / Staff | |
| | Child & Adolescent | Mixed | Access to mental health for young people | |
| | Mental Health Services | Negative | Access to Social Care Services, Waiting Times | |
| Virgin Care | | Negative | Access to Social Care Services | |
| | Children Services | Mixed | Access to Social Care Services, Waiting Times | |
| | Children Services | Negative | Access to Social Care Services, Service Coordination, Waiting Times | |

*NB the comment sentiment column in these tables do not reflect an overall service rating but is rather a categorisation of the nature of the views given on a particular theme.



Themes in relation to social care

When Healthwatch Devon records patient feedback, the experience is categorised in to themes. Depending on how much information is provided, feedback can refer to more than one of these themes. The following are the top 5 themes in relation to social care services.

 Dignity
 Referral

 Service Coordination
 Waiting times

 Safety
 Access to social care services

 Nutrition & Hydration
 Fees and charges

 Choice
 Consultation

 Suitability of provider / staff
 Quality of Treatment

31% of the feedback that was shared with us was given a theme of **access to social care services**. Most of the experiences with this theme were negative. Many of the comments were about people feeling there was a lack of support with social care matters. Knowing how to get help and support were also identified.

Earlier this year my father employed a carer for my mum. The weekly charge was agreed and it was arranged that social services would pay 60% towards this care. However, the weekly charge for the carer has now increased by 72% to more than £1,500 per week. My father will struggle to pay this and will lead to difficult financial circumstances in the near future.

80% of the stories regarding **waiting times** were negative. Most of the experiences shared were regarding children services. In particular, people have been reporting long waits for assessments for the Child and Adolescent Mental Health Services. People also reported that getting the outcome of an assessment also took a long time.

My daughter, who has a learning disability, recently had a reassessment resulting in her hours being cut therefore she will have to be moved within her accommodation. Lady has been caring for her husband at home since he was diagnosed with Dementia. They get one call per year from their GP to check they are ok, but no other advice, help or support. They were unaware of any benefits they may be entitled to, she thought this total lack of support was usual.

All of feedback regarding **Fees and charges** was negative. One family had concerns about the cost of live-in care and how much they were being charged for this service. There was also a complaint about accessing Continuing Healthcare. This was not awarded to one family which meant the carer only received help from nurses at Marie Curie.

Family have been waiting 9 months for the outcome of their son's assessment for autism. They need the diagnosis so they can make the right provisions at school and obtain the correct medication. Their son's behaviour has affected their 9-year-old daughter's mental health, she had been self-harming.

A theme of **choice** accounted for a further 7% of the feedback. These experiences were often linked to issues with fees and charges where people felt their choices became limited.



The feedback regarding **suitability of provider / staff** was split equally between negative and mixed in how the person felt about their experience. The main problem was with service providers being able to offer either appropriate levels of care or the right type of care needed. This was reported in stories relating to both care that was being provided in a residential care home and in care provided at home.

As a family, we have decided to move our mum as we feel that her care needs have increased and the home can't keep pace with the changes that are required. We feel the home's standards need to improve and our mum doesn't have the time to wait for the standards to progress. Care staff levels have been addressed, but there are still issues with care when two members of staff are needed.

citizens ^{advice}

Case studies provided by Citizens Advice in relation to social care services

Rochelle was becoming increasingly frustrated trying to get help and support.

Rochelle is 65 and guardian to her 10-year-old granddaughter Esme. Due to her difficult early years and because of her learning difficulties Esme has emotional problems and is really challenging. For several years, Rochelle had been trying to access support for them both.

When Rochelle got in touch, she was struggling financially and emotionally and the strain of looking after her granddaughter was adding stress. Rochelle was increasingly frustrated that she couldn't access any help.

Rochelle was put in touch with Devon Carers and Devon Information Advice & Support which enabled her to access more support. This help made her feel empowered. The school agreed to provide one to one support for Esme for some of the day. The family were also appointed a guardianship worker, a family support worker and a counsellor for Esme.

The family's emotional wellbeing is greatly improved and home life is more stable. They are now able to make a claim for DLA which will generate extra income for the household.

Rochelle says that the Guardianship Worker and the Family Support Worker have been doing an excellent job for her. And the client wanted to give positive feedback about her social care service.





People's experiences of health and social care services in Devon

citizens advice

Freda had her mobility equipment replaced thanks to social services.

Freda is in her 70s and has mobility problems meaning she required the use of a stair lift. Social services installed one 10 years ago however it had recently broken and could not be used. Freda had rung social services who told her to go back to

the manufacturer. They in turn had said the lift could be replaced at a cost of £1,575. Freda could not afford this, she was living on state pension and had no savings.

Freda did not know what to do. She was convinced that social services would not provide another stair lift and she had rung Care Direct but not heard back. Meanwhile, she couldn't use the stairs and her husband, who has a heart condition, had to 'practically carry her' upstairs every evening.

We rang Care Direct on her behalf and discovered there was no record of Freda's phone call. It

can be hard for someone in a stressful situation to speak up for themselves, or to be aware of their rights. Care Direct updated their notes and said they would respond as soon as possible.

Freda rang to let us know that a new stair lift was being installed, paid for by Social Services.



Experiences shared in relation to social care services

The following are the patient stories that have been shared with us during the last quarter. These stories are sometimes shared by the individual receiving the care, a friend or relative or sometimes reported by an advocate who is providing support.

1. We care for an adult with severe learning difficulties at home 24/7. He is so complex he is unexplainable. Because we are just a normal family we did not know that in giving him a home, rather than him living in care, it would destroy us the way it has. We were just doing the right thing. We had no knowledge of Adult social care and did not need any help or support as he had actually lived with us for many years prior to him coming to live with us permanently. So there was no great change for him or us. We had 2 local businesses, paid for all his needs and never asked for any help. But we embarked on a journey that has irretrievably damaged us and has left us completely demoralised. Individual people were involved in deliberately damaging a family's reputation and as we are just the little people, and have been so humiliated and sickened by the situation we are too downtrodden to do anything about it through fear of another backlash. The whole thing is shocking.



- 2. A relative in our family was moved from the community hospital to a care home at the beginning of last month. Their notes said they were on pureed food, but having spoken to a doctor at the hospital they said they could eat ordinary food as at their age it would not be a problem. At the end of their stay at the hospital they were eating ordinary food, but unfortunately this was not put on the notes. Since being in the home the family have been trying to get them off pureed food with no success. Our relative is always hungry and asking us for food. They have lost weight and it is not very nice for them to be sitting next to someone who is eating proper food. We are told it cannot be changed until they see an assessor which has been on the cards for a month but nothing has happened. What can we do?
- 3. The individual has post-traumatic stress disorder and has recently been diagnosed with autism. They feel there is no support for adults with autism, they live on their own and receive no support for their disabilities, this lack of support and help brings on their PTSD and they then start to feel suicidal. They contacted the autism team but was given conflicting information. Devon County Council arranged a care assessment and the community enabling service was arranged to visit. The enabling team visit was cancelled and they were told that they had been withdrawn from this service. This individual was also on the waiting list for the complex care team. The care assessment team visited and as the client was not in a good way a paid advocate was arranged, this took forever as they went to SEAP first and then they were signposted to Rethink and they visited once when the social workers came to carry out the care assessment. Rethink would only support the individual once and they were told it would not be an ongoing paid advocate service. The disability lead at DCC told the individual they would receive an ongoing paid advocate service for support. The individual is still struggling with their disabilities and anxieties as they still have had not assessment put in place. They have called the complex care team and has been told the social workers are off sick or on annual leave, they have also called the autism team but the manager there is also on leave. They have been told that the care assessment plan still needs to be typed up before it can be put in place. They also feel that they get no support from current GP. They live in council housing and receive housing benefits. The property they live in is sheltered support housing and so they should get a support service for their health and social care needs. These support services have never worked but they are still expected to pay for them and this amount is not included in the benefits. They keep receiving letters saying they are in arrears and they are going to repossess their home. The arrears amount is for the support service. These threatening letters are stressful and brings back the PTSD. When the individual calls the council, they tell them that the support has been decommissioned and there are no support charges to pay. However, they keep receiving the letters.
- 4. Clients 13-year-old son is Autistic and this was obvious from the age of 7 years. His primary school were unable to help him and he has since been excluded from 2 mainstream secondary schools for behaviour problems. He is now attending the pupil referral unit and has met a bad crowd and has been caught shop lifting and taking drugs. In all of this time (6years), the family have still not received a diagnosis of their son's condition and have been on a waiting list with CAMHS at Virgin Care since Jan 2016 (when he was re-entered onto the system) waiting for an assessment to achieve diagnosis. Family are being ripped apart by this and feel abandoned and let down. Client does not know where else to turn to get help for her son.



- 5. This individual finds caring exhausting and has very little time to themselves hence the late response to the survey regarding the New Carers' contract. This carer would like to know if there are printed information leaflets on Financial Assessment and does Westbank have any at their organisation. This individual does not have access to a computer and requires written information rather than verbal. What are short breaks and other personalised support as specified in the carers support plan and personal budget? The individual would like to know how to join the Carers Trust CarerSmart Discount Club when you do not have access to or use a computer? The individual thinks that two way communication is vital especially for those carers who cannot get to carers meetings. The individual has stated food prices have risen since the end of last year and do care workers know which carers are struggling with heat or eat? The individual knows that there are some carers that do not like to ask.
- 6. Individual called and left a message re help for getting a mobility scooter as she is elderly and has limited mobility.
- 7. Client has had a blue badge since being medically retired in 2010 and now has been refused one, even though their condition had not changed. Client will appeal this decision.
- 8. My husband died of cancer last year and we had no help whatsoever. Continuing Healthcare wasn't granted and he needed 2 people to lift him. The only people that helped were the nurses at Marie Curie. Continuing Healthcare wouldn't pay. I have complained to the CCG that my husband's end of life care was appalling. I have also reported this to the CQC. However, it is too late to do anything now though.
- 9. My elderly husband was admitted to a care home after a stroke. I asked for advice for filling out his personal financial assessment form. I was told a member of staff would arrange a home appointment. After 3 weeks of waiting I rang DCCs charging for care services and was

told - sorry I forgot, I have been busy. I was too stunned to make a reply. A week later I still had not heard anything. I am disgusted. The member of staff promised to send me a new appointment letter. I have very bad mobility problems myself and a very painful right shoulder. I am also elderly suffering with peripheral neuropathy and this combined with my other pain disturbs my sleep.





- 10. Clients child attended a special needs school from 2011-2016 where his speech and language therapy was withdrawn and his one to one provision was withdrawn. Client was told this was a decision made by DCC as attending a special needs school was deemed enough. Eventually, the client had to go outside of Devon to obtain full reports and recommendations tailored made for her son to establish what support he actually needed and the client paid £100s for this. It was not available in Devon. Son suffers Downs and Autism. She went on to say that the replacement 'statements' for special needs children (education, health and care plans) have retained the same criteria but they are no longer tailored to the individual needs, they are largely broad-based recommendations, referring them to websites etc and, regularly, do not include housing or medical needs input.
- 11. This lady needs support, information and advice on raising a complaint about a care home where her son was a resident. Her son suffers with bi polar, kidney and leg problems, he is physically disabled and gets about in a wheelchair. He was recovering from treatment on his legs at a community hospital and needed to go into a care home when he was discharged. They selected a home which they then visited. The home promised a good service and care for their son and fees were never mentioned. However, when he moved in, the bed was not ready, it was a small dark room so a hoist would not fit, could not even fit a chair or commode in to the room. The son spent the 2 months that he was resident there in bed, he never got out. There was not TV in his room, his mum arranged that for him. The bed clothes were never changed and the room was not cleaned, nor was the bed pan properly washed, just rinsed out. They never checked his diet but they have been charged £1000 per week for this service of care. The elderly mum now owes £8000 for the 2 months which she cannot pay. Her son has been moved to a home which they are now much happier with.
- 12. Client has a son with Downs and Autism (now 19-year-old). Client says Virgin Care offered him limited therapies (e.g. OT only available 9 hours per week) and she attended and won two tribunals to obtain the right treatment for her son. Their 17-year-old daughter has been diagnosed with Dyslexia and Autism, but client had to pay privately for this diagnosis as schools would not recognise a problem and Virgin Care waiting lists were shocking, plus they never met the NICE guidelines. Virgin Care agreed to keep the key workers from the outset (2006), which provide links between all the support organisations available and are a tremendous help to parents, but they now have none, according to this client. The NICE guidelines state that under 19-year olds are entitled to a key worker, but Virgin Care north Devon have no key workers.
- 13. Clients 10-year-old daughter, who was diagnosed with Autistic Spectrum Conditions in 2014, has difficulty using a pen to write and cutlery to eat and client feels that she should be referred to an OT for coordination and movement coaching. However, the SENCO at her primary school refutes this and told client that her daughter does not meet the criteria. Client then tried the single point of access for Integrated Children's Services in Devon, a service provided by Virgin Care on behalf of the NHS, but found the online process confusing and difficult and was not able to complete the process.







14. Communication, or lack of, is an issue for parents who are seeking help through CAMHS. Frustration that systems do not talk to each other and that children's and adults mental health services are not joined up. An assumption that someone is leading their child's case, particularly if the child is in school, but what happens to children who are not attending school? Who is coordinating their support? Parents felt that this falls to them and they find it exhausting. Parents spoke of a lack of support in the community following discharge from inpatient care. The question was raised: is there a community mental health worker for CAMHS? If so, how do we access this service? The distinction between the criteria for children's and adults mental health service is lacking. Concern that a child who receives support through CAMHS may not be eligible when they transfer to adult MH services. A need for clarity around this early on is essential in preparing the young person for the next stage. Need for more information available to parents as to

what services their child can access. There is a list of services on Devon Partnership Trust website for adults but parents not sure where to find info re what services CAMHS provides. Very often a young adult will be unable to fight for support and rely on parents as advocates to help them to access the support they need. Access to services can be difficult. Crisis care parents have been at their wits end when their child / young person has made attempts on their life and yet still have to wait too long for support. What constitutes a crisis? Information provided in written correspondence should be explained more clearly, using plain English and clear instructions where necessary. Parents expressed how puzzled they have been when letters have been sent to them, not knowing where exactly they are in the 'system' and who they are dealing with. There is a need for parents and young people to be informed about the range of support that is available to them, not just counselling. Different approaches suit different people. Some young people who enter into adult MH services find group therapy intimidating / inappropriate. Particularly if they are 18 and others in the group are much older. Attitudes of staff - that staff in children's inpatient units (in their experience) were more caring than on adult wards. Parents felt that there is a lack of focus on outcomes. Some had no idea what was set out in a care plan for their child and what they were aiming for outcome wise. They had not had the conversation. Should this not be done early on with full involvement of the family / individual so that they know what they are working towards? There was a general feel of a lack of confidence in mental health services.



- 15. Clients daughter suffers with severe Autism and ADHD. When social services got involved the social worker removed the mother (who suffers from bipolar) from the home and referred the family to child protection due to the daughters behaviour. The social worker also placed their young son with a relative and discussed a possible permanent placement with them, without consultation with the parents. Clients requested twice to change social worker, but both times were refused. However, the individual is now no longer their Social Worker and the family have since been taken off the child protection list. Their daughter is in a great school that is equipped to handle her needs, mum is taking medication and living back at home, as is the young son. They feel this particular social worker made their problems much worse.
- 16. A family has concerns regarding the care and cost of live in care for one of their relatives. The family live out of area and are not happy with the charging and the unprofessional manner of the company providing the care. Yes, the charges have gone up due to care staff being paid more money for live in care, this has been a change in the law. However, the family are not happy with the way they have been charged for recent care. The family has read the terms and conditions and their contract, this extra charging is not stated in either of the documents. The carers are stating they do not get a statutory 2-hour break as they end up working it. The relative being cared for also has a family member living with them and they say this is not the case. The company is now charging the family for the extra 2 hours. The carers are saying to their employer that they are working more than 10 hours a day.





Primary care

The following are the views regarding primary care services including GP practices, pharmacies, dentists and opticians. The table also shows the sentiment expressed by the person explaining how they felt about their experience and the theme(s) relating to the feedback. See appendix 1 for more information on themes.

| Service provider | Comment sentiment* | Themes relating to the feedback | |
|-----------------------------------|-----------------------|---|--|
| Brunel Medical Practice | Negative | Appointments, Consultation | |
| Chagford Health Centre | Positive | Staff attitudes, Waiting Times | |
| Christow Surgery | Positive | Access to GPs | |
| Cricketfield Surgery | Positive | Quality of Treatment | |
| Day Lewis Pharmacy - Tavistock | Negative | Medicine management | |
| IR Peacock Chemist | Positive | Consultation, Quality of Treatment, Staff attitudes | |
| Litchdon Medical Centre | Positive | Quality of Treatment, Staff attitudes | |
| | Positive | Quality of Treatment | |
| Mount Pleasant Health Centre | Positive | Quality of Treatment, Referral | |
| NHS Business Services Authority | Negative | Consultation, Fees / Charges | |
| Northam Surgery | Negative | Staff attitudes, Waiting Times | |
| The Foxhayes Practice | Neutral | Appointments | |
| The Courth Louis Medical Dractice | Positive | Quality of Treatment, Staff attitudes | |
| The South Lawn Medical Practice | Positive | Appointments, Staff attitudes | |
| Topsham Surgery | Positive | Quality of Treatment | |
| Unknown GP 1 | Negative | Fees / Charges | |
| Unknown GP 2 | Negative | Choice, Staff attitudes | |

*NB the comment sentiment column in these tables do not reflect an overall service rating but is rather a categorisation of the nature of the views given on a particular theme.

Themes in relation to primary care

When Healthwatch Devon records patient feedback, the experience is categorised in to themes. Depending on how much information is provided, feedback can refer to more than one of these themes. The following are the top 5 themes in relation to primary care services.

Service Coordination Consultation Access to pharmacy Choice Staff attitudes Access to dentistry Waiting Times Appointments Quality of Treatment Records management Diagnosis Fees / Charges Access to GPs

In relation to primary care services we found that a third of the feedback received was given a theme of **staff attitudes**. Most of the experiences with this theme were positive. Comments shared regarding staff attitudes included nurse being friendly and helpful and my GP is very friendly and helpful.

I had an appointment with my GP for my eye test. It was a good experience and they dealt with my enquiry.

Two thirds of the stories with the theme of **consultation** was negative. People feel that they are not being given all the required information. People also felt they are not being properly consulted regarding the choices available nor given a say in some decisions regarding their care.

I can always get an appointment at my surgery. My GP is very friendly and helpful.

All of the feedback regarding **fees and charges** was negative. Comments regarding the changes in policy by Northern, Eastern and Western Devon CCG on prescribing of gluten free products has attracted quite a lot of feedback. People are unhappy that products that were previously available on prescription will no longer be provided. Wonderful man. Very quick and efficient. Excellent medical advice. Good explanations of medicines and treatments. Remembers medical history of patients and what they can take with other medicines. A brilliant chemist, efficient, knowledgeable, and lovely manner with a personal touch.

Quality of treatment attracted a further nearly a quarter of the feedback. All of which were positive. People are happy with their experience and the service they receive.

At my annual asthma check the nurse said they were going to change my meds. The pharmacist explained it all, the upshot was I had no choice but to change my meds which had been working very well for me. I had no say or input at all. I wasn't happy with it but had no chance to ask questions or to say anything.

People have been told that time for **appointments** are being reduced because of staff shortages.

Man is a full-time carer for his partner and they have been living off benefits. They have been struggling financially and not been able to afford prescriptions, eye tests etc. However, because they claim income support this automatically exempts them from these health costs, but nobody advised them of this.



citizens advice

Case study provided by Citizens Advice in relation to primary care Mary and Arthur were stressed and anxious and felt their voices were not being heard.

An elderly couple, Mary and Arthur, needed some advice after they had received letters from NHS Business Services Authority. NHS BSA were demanding payment of two fines totalling £184, plus dental and prescription costs of £104.30.

Following an unexpected change to their benefits and confusion on their part the couple had incorrectly completed a prescription and dental charges form. It was a genuine error and the couple immediately paid back the amount owing for the dentistry treatment and for the prescriptions.



However, the NHS BSA were unwilling to write off the associated fines and continued to demand payment of £100. Arthur was claiming benefits and Mary had a low paid job which meant that finding an additional £100 from the household budget was extremely difficult. They tried calling to discuss their situation but were unable to get through. A month later they received another letter stating the penalty had risen to £150. They were stressed and anxious and felt their voices were not being heard and didn't know how to proceed.

We wrote to NHS BSA, asking them to consider writing off the outstanding payment, as Mary and Arthur were in the process of applying for an HC2 Certificate. But they insisted that Mary and Arthur should pay the fines, but suggested they could apply for a refund if the certificate was awarded. Mary and Arthur agreed to this and we helped them set up an affordable payment plan to repay the fines monthly. The first payment was paid by cheque,

which was accepted. The following month the cheque payment was rejected and another £50 was added to the fine. When Mary and Arthur told us, we made several more attempts to contact the NHS BSA. They were becoming very stressed and upset by the whole issue.

Finally, we made contact with the NHS BSA but found it was very difficult to speak to the right person and to get consistent information. We decided to write a complaint. Very sadly, before the complaint could be investigated, Mary had a heart attack.

We pursued the complaint and eventually NHS Business Services Authority closed the account, cancelled any outstanding fines and sent a refund for the amount they had paid in fines.

The good news is that Mary and Arthur are both ok and Mary is recovering well.



Experiences shared in relation to primary care services

The following are the patient stories that have been shared with us during the last quarter. These stories are sometimes shared by the individual receiving the care, a friend or relative or sometimes reported by an advocate who is providing support.

- 1. Went for appointment at my GP surgery for an itchy scalp. GP was very nice, they checked everything and I was very pleased with the service.
- 2. Me and my mum went in for some blood tests. It was very quick, no problem.
- 3. I went to my GP surgery in March. There was no delay on the appointment and I was seen by a nurse to treat my infected toenail. The nurse made me feel that she just wanted to finish with me and get on to the next patient. She misheard what I said when she spoke to me. She never made eye contact when she spoke to me, just looked at her computer all the time. The feeling was not good when you are talking about your problem to the nurse and they are too busy to listen as they doing something at the same time.
- 4. I recently went to have my blood pressure checked at my GP surgery. It was high and so was prescribed medication to lower it. I was also told to continue to take my diabetic tablets.
- 5. An individual reviewed their local health centre as a 5 star rating and would extremely likely recommend this service to friends and family. They found the experience professional, speedy and on time.
- 6. I am 83 and partially sighted. My medications used to be the same every month but now they are completely different. The same medication in the same dosage changes in brand, packaging, colour, size and shape. This makes it almost impossible to manage. I have been told the pharmacy chain goes with the cheapest deal for each drug when they do their ordering and so the packaging etc changes frequently. I have spoken to my local pharmacist who told me they get lots of complaints about this.
- 7. The North, East and West Devon Clinical Commissioning Group have a new policy regarding gluten free food. Prescriptions will be withdrawn for adults. Children under 18 years can be prescribed bread, flour mixes and pasta. I have Coeliac Disease. prescription staples have been prescribed for me by the dietary department at Exeter and Devon Hospital after my diagnosis. I will have to find fairly priced bread products to ensure a balanced diet. The price of these breads is very expensive. While I can manage to buy these products, I worry for those who live on a very small amount of money, pension, wage etc and who are old, frail, ill, etc. How will they be able to afford these foods. If they do not have them their health is in greater jeopardy! Who will fight their corner?
- 8. My GP was very helpful with my health care needs. They did refer me quickly to hospital for further treatment. I am happy with my care.
- 9. My GP is brilliant, you can drop in anytime if you need something.



- 10. Several visits to a GP surgery and seeing several different GPs has finally led to being told my symptoms point to Fibromyalgia. There was no follow up from this diagnosis. I was left having to self-research what this meant and seeing as this is a lifelong condition fears of how this will impact my future and working life. I struggle on a day to day basis trying to juggle work and parenting whilst feeling constantly in pain, exhausted and with no indication of this ever getting better. On further visits to the GP I was prescribed some medication to take every day, there was no alternative support or treatment offered despite my hesitation to start taking medication for a condition that is lifelong so presumably the medication will also be lifelong. I don't want to mask the symptoms of my condition, I want to understand it, accept it and learn how to manage it through exercise, diet and good mental health. The response from the GPs is that although there is a clinic which can support this I cannot be referred unless I have tried medication first. I find this completely disempowering and on a practical level surely this is far less cost effective for the NHS. I have now given up trying to access professional support and instead live trying to balance my energy between work and parenting, letting work down constantly due to sick days and fearing what this means for my future income and career. Living in constant guilt at not having the energy I want to give to my young children and not knowing how to simply have some advice to manage it all. I feel let down and dismissed by the GPs and feel that I am being penalised for wanting to have a say and control in my own condition management.
- 11. My GP dealt very well with my needs and I am very happy with the service.
- 12. I had my routine blood test at my GP surgery my blood was taken by the nurse. The nurse was friendly and helpful, but as I have very small veins it makes it very difficult to find them.





Mental health care

The following are the views regarding mental health services. The table also shows the sentiment expressed by the person explaining how they felt about their experience and the theme(s) relating to the feedback. See appendix 1 for more information on themes.

| Service provider | Comment sentiment* | Themes relating to the feedback |
|--|-----------------------|--|
| | Negative | Access to mental health Services |
| Community Mental Health Team | Negative | Appointments, Choice, Referral, Access to mental health services |
| | Negative | Choice |
| Community Mental Health Team - Honiton | Negative | Waiting times |
| Devon Memory Service - North Devon | Negative | Access to mental health services |
| Frenklyn Heeritel | Negative | Discharge, Service Coordination |
| Franklyn Hospital | Positive | Quality of Treatment, Staff attitudes |
| The Cedars | Negative | Choice, Consultation, Quality of Treatment |
| West of England Specialist Gender Identity Clinic | Mixed | Suitability of Provider / Staff |

*NB the comment sentiment column in these tables do not reflect an overall service rating but is rather a categorisation of the nature of the views given on a particular theme.



Themes in relation to mental health

When Healthwatch Devon records patient feedback, the experience is categorised in to themes. Depending on how much information is provided, feedback can refer to more than one of these themes. The following are the top 3 themes in relation to mental health services.

Dignity Quality of Treatment Referral Service Coordination Waiting times Choice Suitability of Provider / Staff Access to mental health Services Safety Discharge Appointments Consultation Staff attitudes

In relation to mental health services we found that 19% of the feedback received was given a theme of **choice**. All the experiences with this theme were negative. People did not feel they had sufficient choice in accessing the different mental health services available and choosing which might be appropriate for them. People felt they had a right to decide which services they would like and how they want to be supported but this choice was not available and decide professionals were making these decisions on their behalf.

A single point of access for mental health services, it took 10 telephone calls. Lucky for me I am on a contract phone, otherwise I would have run out of credit.

12% of feedback included the theme of **quality of treatment**. One person told us they received wonderful care they at Franklyn Hospital. But another was unhappy with their care whilst in the Cedars. Changes in staff and therefore continuity of care was an issue for some. Person was referred to a caseworker but they suggested they met in a public place. They were unhappy with this as they felt it was unprofessional, so the support stopped. The GP then made a referral to a counsellor who said they needed a psychiatrist so this also stopped. The person was then referred to the Depression and Anxiety Service, but their disorder was too severe for DAS to support. The psychiatrist won't see them again as it was only 6months since they met, so they have no support or help at all.

People are finding it difficult **accessing mental health services**. Getting through to the right services and services are not responding following referrals.

Person spent some time in Franklyn Hospital. They stressed that the care was wonderful and the medical staff were very supportive and understanding. However, the discharge was not completed well and there were also issues with service co-ordination.



Experiences shared in relation to mental health services

The following are the patient stories that have been shared with us during the last quarter. These stories are sometimes shared by the individual receiving the care, a friend or relative or sometimes reported by an advocate who is providing support.

- Client was diagnosed with dementia last year and invited to attend the Memory Clinic at North Devon District Hospital where they were told that they would refer them to the Alzheimer's Society for ongoing support. Client has never heard from anyone since. Carer feels the Memory Clinic was a waste of time and is left to support the client by themselves.
- 2. Client was sectioned and after being in The Cedars was sent to another part of the UK for treatment. At the other unit, the individual had to find out how to get home and trains were limited, so booked a taxi home. Devon and the other unit are now arguing over who should reimburse the client. Also state that the individual could have taken cheaper journey and that they would have given advice on how to get home. Client states that this was never offered. They have agreed, under protest, to having a community psychiatric nurse, which has now changed 3 times since last year. Individual feels that if this is the state of mental health care, they would rather look after themselves.
- 3. The client is a young man who is under the Laurels and in the early stages of gender reassignment. He has attended the Laurels support group, but has been disappointed by the fact that the other members are nearly all a lot older than him.
- 4. Mental health service and seeming abdication of responsibility for help aid needed by people, especially vulnerable persons, and those experiencing problems for the first time, many of whom have had little contact with, and may not even have a GP, to voluntary bodies who do tremendous unfunded work but with little experience and training. Even ReThink has now had budget cuts so that it cannot act as a drop in place. Vulnerable people now are reliant on purely voluntary organisations totally unfunded by NHS. This is totally unacceptable behaviour. In Exmouth, The Open Door Centre is all that there is unless you have some kind of

referral. They, in effect, are the equivalent of the ambulance service which is totally funded by the NHS for physical illness. This situation just goes on and on despite government promises, and endless silence or excuses from the responsible Trusts and Care Commissioning Groups. It is time Healthwatch Devon shouted loud and clear.





Responses to the report

We welcome responses from commissioners and providers to the comments we have received from the public. Whilst we have published this overall report, every individual who contacts us is given the opportunity for support in raising their issue directly with the provider. In some cases, this is not possible because the contributor has not left their details or given consent to share personal details, however, we are under an obligation to report on what people have told us.

We hope this approach will encourage providers to share their concerns with us as well as enabling people to engage in a constructive dialogue about how services could be improved. If a service is valued we welcome that feedback. In all our work we encourage people to share the good with the bad and tell us what is working well for them.

The Care Company (SW) Ltd

I would like an opportunity to respond to the negative comment that has been made regarding our fees/charges. It is true that our fees were increased by 70% in respect of live in care at the end of June of this year. This was not something that as a company we wanted to do, but were forced to do so with a change in the law surrounding sleep in services.

As a company, we rely greatly on our legal advisers in respect of changes in the law and when we were informed that we need to ensure that our staff are paid at least National Living Wage for all the hours they remain on duty, including those that they are asleep, we followed their advice appropriately. We totally sympathise with the fact that this has had a massive financial impact upon our clients and would never have applied the change had it not been for the change in the law.

Clearly, this has had and will continue to have a huge impact upon the industry as it will affect all services that involve night sleep situations. As a company, we tried to provide as much detail to service users as possible as the information became available to us, although this was not easy as the matter was complicated in detail. The entire uplift was passed on to our staff in the way of a pay rise who are now remunerated in accordance with the new employment law. As a result of the uplift only one service user terminated our live-in care services as they are all very satisfied with the care we provide. Our clients benefit from great continuity from the live-in care service, with one to one input proving to be a highly successful way of people remaining in their own homes as opposed to going into residential care.

As a company, we have a rigorous quality assurance process, both internally and externally with all feedback being welcomed. Recent feedback from our clients is very positive in relation to the service that we provide. Additionally, our latest inspection report displayed on our website has a true reflection of what both service users and staff think of the company www.thecarecompany.org

Sarah Sabater, Managing Director



Cricketfield Surgery

How lovely to see so many positive comments around primary care, including our practice. Tracy Green CMgr FCMI, Practice Manager

Mount Pleasant Health Centre

I was pleased to see that the comments relating to our service are positive. Julie Croze, Practice Manager



When Healthwatch Devon records an experience, there are a list of categories to which the feedback can be themed. Depending on how much information is provided, feedback can refer to more than one of these themes. The table below shows a list of all those themes and the definition of each.

| Records management | Access to hosp | oital services ° | omplaints process |
|------------------------------|-------------------------|-----------------------------|----------------------|
| Appointments | Quality of tre | | Service Coordination |
| Waiting times | Diagnosis Admission | Safety Confidentiality | Consultation Dignity |
| Dignity Patient transport | Suitability of provider | Monitoring & Accountability | Fees and Charges |
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| Theme | Definition |
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| Access for people with a physical disability | Access issues due to physical disability (e.g. wheelchair access) |
| Access for people with a sensory disability | Access issues due to sensory disability |
| Access to Dentistry | Other access issues regarding dentistry |
| Access to GPs | Other access issues regarding GPs (e.g. Availability) |
| Access to Hospital Services | Other access issues regarding hospital services (e.g. layout) |
| Access to Opticians | Other access issues regarding opticians |
| Access to Pharmacy | Other access issues regarding distribution of medicines (e.g. repeat prescription |
| Access to Social Care Services | Other access issues regarding social care services (e.g. availability of social worker) |
| Admission | Entry to a treatment pathway that is appropriate and timely |
| Appointments | Easy access to appointments |
| Car Parking | Ability to access the service via parking |
| Choice | Providing alternatives and allowing them to be picked from |
| Cleanliness | A clean environment free of hazards |
| Complaints Process | Having a system which allows for the raising of concerns, and also feedback and action in relation to those concerns |
| Confidentiality | Keeping personal details safe and undisclosed unless permission has been given for them to be disclosed |
| Consent | Asking permission before performing an action which affects another |
| Consultation | A meeting with an expert, such as medical doctor, in order to seek advice |
| Diagnosis | Understanding the need that needs to be met in an effective way |
| Dignity | To treat someone with dignity is to treat them as being of worth, in a way that is respectful of them as valued individuals |



| Theme | Definition |
|--------------------------------|---|
| Discharge | Exit from a treatment pathway that is appropriate and timely |
| Equality | Treating everyone the same regardless of any perceived difference |
| Fees / Charges | Issues with services that require payment (e.g. dental treatment/ sick notes) |
| Monitoring & Accountability | That the performance of the service is being monitored, poor performance is addressed and it is clear where responsibility lies |
| Nutrition & Hydration | Easy and appropriate access to proper nutrition and water |
| Opening Hours | Access to services at appropriate times |
| Patient Transport | Ability to access the service via patient transport |
| Privacy | Not undermining a person's self-respect, including respecting a right to a private life |
| Procurement / Commissioning | The buying and contract management of services |
| Quality of Treatment | High quality procedures, the right medication etc. |
| Records Management | Systematically controlling the creation, distribution, use, maintenance, and disposition of recorded information |
| Referral | The act of referring someone for consultation, review or further action (e.g. the directing of a patient to a medical specialist by a GP) |
| Safety | Being protected from danger, risk or injury (including health and safety issues). |
| Service Coordination | A seamless link between health and social care services so that if more than one service is involved in meeting a person's health and social care needs, they work together in a joined-up collaborative way |
| Service Monitoring | That the performance of the service is being monitored, poor performance Is addressed and it is clear where responsibility lies |
| Staff Attitudes | Members of staff having a friendly and helpful manner |
| Staffing Levels | Availability and capacity of staff |
| Stigma | Stigma is a perceived mark of disgrace that sets a person apart, which can bring about feelings of shame, blame and distress |
| Suitability of Provider Staff | Staff who have the skills, time and resources |
| Waiting Times | Easy access to timely appointments |

The data included in the experience summary reports are for the recipients to utilise and to help inform service design, delivery and improvement.

In addition our database is set up so that we can filter these themes allowing us to identify emerging topics. We will then look in more detail and extract feedback regarding these topics and feed them into specific commissioner/trust reports and sometimes look to produce a specific report.



This report has been produced by Healthwatch Devon - the independent champion for health and social care in Devon. We would like to thank everyone who took the time to share their experiences.

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