



Public Health
Agency

Primary Care

Summary of feedback on Care Opinion platform

August 2020 - March 2022



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1.0 PURPOSE

The purpose of this briefing paper is to demonstrate how the current Care Opinion database can be used to inform leaders and key stakeholders within the Health and Social care system on the experiences of patients, families and carers engaging with Primary Care services. The following information reflects the stories published on Care Opinion from 03 August 2020 to 31 March 2022 in relation to Primary Care services across Northern Ireland. The analysis includes stories which reflect upon Primary Care including General Practitioner (GP), Pharmacy, Nursing, Multidisciplinary teams and administration teams, including reception.

2.0 BACKGROUND

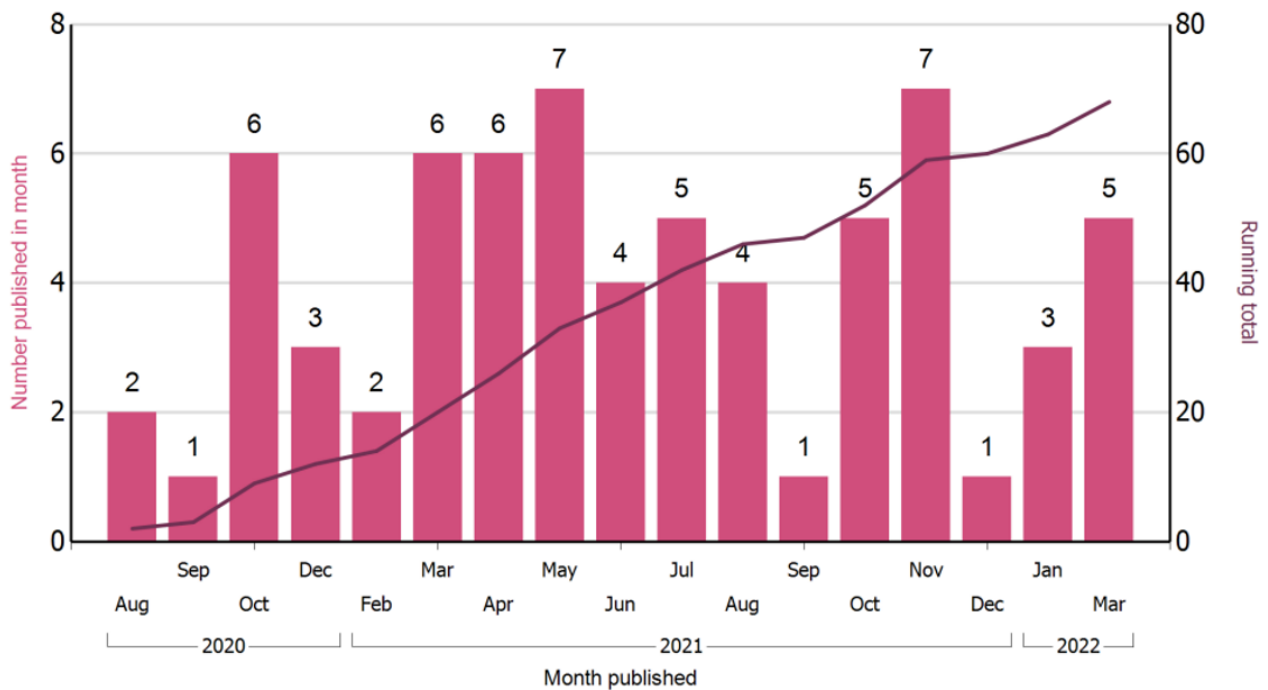
The Online User feedback platform, Care Opinion, was launched in Northern Ireland on 03 August 2020 as a new opportunity for patients, families and carers to share feedback on their experiences of services within Health and Social Care in Northern Ireland. This project detailed within the Programme for Government highlighted the need to embed a system for feedback which is open and transparent and will support services to engage with the voice of patients, families and carers. The Care Opinion platform facilitates a continuous feedback loop between the services and the author of the feedback, with all stories moderated before publication on the website (www.careopinion.org.uk).

The opportunity to engage with authors through Care Opinion was presented to the key stakeholders for Primary Care in January 2020 with an emphasis placed on the governance arrangements relating to data management and the role of moderation. Although specific promotion through Primary Care was not agreed following subsequent meetings it is recognised that authors share their experience of a full journey and will often include the interaction with Primary Care services. Therefore, it is important to outline the key themes for learning and to present the voices of patients, their families and carers to influence and shape services in Primary Care.

3.0 CONTEXT

In total **68** stories have been shared through Care Opinion. 50 of these stories relate to a specific GP practice with a further 18 stories where the GP practice cannot be identified. Figure 1 displays the number of stories published each month since the launch of Care Opinion on 03 August 2020. The method used to submit the stories were via the Care Opinion Website (n=66, 98%), Leaflet (n=1, 1%) and Kiosk (n=1, 1%). Stories can also be shared using a freephone number hosted by Care Opinion.

Figure 1: Number of stories submitted each month on Care Opinion



These stories are submitted from across the geographical areas of Northern Ireland in ascending order:

- County Fermanagh 2
- County Tyrone 4
- County Londonderry 7
- Unknown 9
- County Armagh 14
- Co Antrim 15
- Co Down 17

Authors are asked to identify if they are a patient/service user, relative, carer etc. The responses given are shown in Table 1. The majority of stories have been submitted from the perspective of the patient/service user (n=57, 84%).

Table 1. Which term best describes you?

Term	Number	Percentage (corrected to closest whole denominator)
Patient/Service User	57	84%
Parent/Guardian	5	8%
Relative	3	5%
Staff member (posting for a carer/relative)	1	1%
Friend	1	1%
Carer	1	1%

4.0 SUMMARY OF STORIES

Care Opinion is built upon the concept of “what’s your story” and supports the author to highlight what matters most to them using their own words. As part of the analysis through Care Opinion, each story is assigned a criticality score by an independent moderator to highlight the level of critique included in the story. Figure 2 illustrates the scores for the 68 stories submitted relating to Primary Care.

Figure 2. Criticality rating of stories submitted on Care Opinion relating to Primary Care

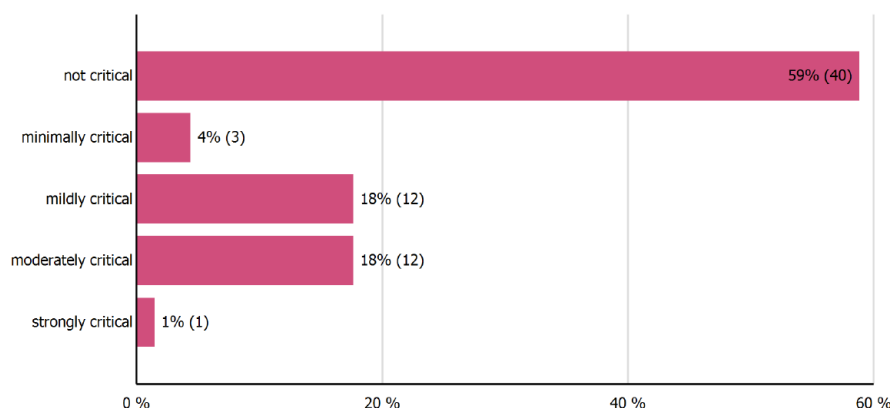


Table 2 outlines the definition of each criticality score and provides examples of the emerging themes taken from stories which relate to Primary Care.

Table 2. Definition of Criticality scores as assigned by Care Opinion Moderators

Score	Definition	Examples from Primary Care stories	n=
0	Not Critical: Entirely positive or neutral postings with no hint of criticality.	Ease of access; clear information; staff behaviour; staff attitude across whole team; appropriate referral; follow up care; shared decision making; efficient service; professionalism; individualised care; access to tests.	40
1	Minimally Critical: Mention of dissatisfaction with non-clinical non-personal aspects of care, typically “facilities” issues such as waiting.	Reduced access to GP – support received from other staff.	3
2	Mildly Critical: More specific but still mild criticism, which may also include non-clinical but interpersonal issues such as attitude of staff, compassion, politeness. This might include the timely nature of the service where it has caused distress	Difficulty contacting surgery; unreturned telephone call by GP; prescription issues; social distancing arrangements; unable to register with GP Surgery; staff behaviour; staff attitude; communication.	12
3	Moderately Critical: Criticism which may include alleged shortcomings in clinical or non-clinical aspects of care; Also includes serious comments about facilities where people’s essential basic care needs are not being met	unable to access GP care; feeling let down by service.	12
4	Strongly Critical: Serious criticisms of specific unnamed staff or groups of staff, or of clinical or other care or facilities. This may have had very serious consequences for physical or emotional health.	Communication concerning misdiagnosis.	1

There are also three supporting questions included on the platform:-

- 1- What was good about the experience?
- 2- What needs to improve?
- 3- What are your feelings and emotions relating to your story?

Responses relating to Primary Care are summarised in Table 3 and further illustrated in the word clouds within Appendix 1.

Table 3. Tags to describe experience on Care Opinion relating to Primary Care

<i>What's good?</i>		<i>What could be improved?</i>		<i>Feelings</i>	
staff	19	communication	6	thank you	17
Care	14	staff attitude	4	at ease	7
efficient	9	access to care	2	cared for	7
nurses	9	access to GP	2	grateful	6
professionalism	9	access to specialist services	2	given up on	5
advice	8	call back	2	helped	5
caring	8	Lack of care	2	upset	5
reassuring	6	pain management	2	anxious	4
support	6	patient care	2	fantastic	4
compassion	5	staff introduction	2	let down	4
compassionate	5	treatment	2	put off	4
friendly	5			reassured	4
helpful	5			supported	4
professional	5				

In the following section the emerging themes from the tags and criticality scores are illustrated using quotes taken directly from the stories shared. It is important to highlight that the themes are not mutually exclusive and a number of themes can be identified within the quotes.

5.0 THEMATIC ANALYSIS OF NARRATIVE

5.1 What's Good?

5.1.1 Patient Client Experience Standards.

Through exploration of the positive experience the approach of staff within Primary Care is highlighted as an emerging theme. These can be mapped to the Patient Client Experience standards which are considered consistent with high standards of care and compassion.

- a) Communication
- b) Respect
- c) Privacy and Dignity
- d) Attitude
- e) Behaviour.

Although some may consider these basic skills, they are fundamental to the experience of patients and their families; the quotes also highlight the challenging contexts around the care and the importance of the approach of the GP or the wider team, making a significant difference to the patient and family experience.

a- Communication

"...I have had a number of telephone consultations with my GP practice in last number of months. Dr XXXXX was absolutely wonderful during those consultations, she put me at ease and made a very difficult time for me so much easier. I worried that over the telephone I wouldn't be able to convey what I needed, but her professionalism and above all kindness meant it did not matter. I feel that in these times our GPs who are doing an excellent job should be applauded..." (903546)

"...Some weeks back our GP, who has been so helpful and supportive, contacted us to inform us that our brother was putting his life in danger and that he felt that he needed to be sectioned under the Mental Health Act. We both supported this action as we had been telling the disability social worker that our brother could not look after himself.. The family GP listened..." (791475)

b- Respect

"...Daughter with severe learning difficulties petrified of syringes refusing to take Coronavirus injection...Dr XXXX came to our rescue... Not deterred by this very challenging situation Dr XXXXX took the time to discuss a way forward and put into place a plan of action, knowing that time was of the essence for our daughter to have this vaccine ASAP. One week later Dr XXXXX returned to our home and the plan agreed was put into effect. With perfect timing, full consideration of our daughters needs and a wonderful caring and compassionate attitude our daughter this morning, to our relief, received her first vaccine dose. I would like to place on record my sincere thanks and appreciation to Dr XXXXX for her professional, caring attitude and assistance, regarding what has been a very stressful time for our family. It's great to see a GP who is prepared to go the extra mile for their patients especially one like our daughter with so many challenging intellectual and health issues..." (831352)

"...The receptionist at XXXXX Practice was warm, efficient, and helpful. She arranged an urgent call with Dr XXXXX, who asked me to send through a photograph. I was sent a secure link, uploaded my photo, and was phoned back soon afterwards. Dr XXXXX decided to refer me to the dermatology clinic, and listened to my preference to attend RVH... Dr XXXXX was great - putting me at ease, asking all the right questions, really listening to me, and then organising the referral swiftly and effectively..." (809814)

c- Privacy & dignity

"... XXXXX (Nurse) was great from the start in being very informative; she explained the procedure of what to expect with the smear test and then when to expect to hear from them with results if necessary. She made me feel very comfortable in what can be an uneasy situation by chatting to me and letting me know what she was doing. XXXXX was very professional, she ensured that she was being conscious of all necessary PPE as well as being compassionate throughout the procedure. Due to her manner I would have no concerns in going for another smear test in future years..." (792779)

d- Staff attitude

"...My son is 20 and is autistic with severe learning disability...I had already discussed his needle phobia with the practice...He was surprised at how little it hurt and super proud of himself for managing it. The nurse told him he'd been the best person she'd injected all day and he was delighted. It was all made possible because the nurse was skilled, empathetic to his needs and calm. She understood how terrified he was but put him at ease..." (826557)

"...I see my Nurse (XXXXX Medical) every 12 weeks for a procedure. I want to say how proud of them I am. Throughout the whole of last year during this horrible Covid-19 situation, the Nurses have ALWAYS been polite, positive, optimistic and very cheerful..." (826912)

"...Thank you to Dr XXXXX and the staff in XXXXX Medical Practice and the staff in XXXXX A&E department, who looked after our child with great care! They all put our child at ease and made him smile..." (921429)

e- Staff behaviour

"...When we arrived in our car the GP asked us both if we were well and the usual pre-vaccination questions, then administered my husband's jab and came round to my side of the car to give me mine. It was all done with the minimum of fuss and we felt very safe from COVID-19 as we didn't have to get out of our vehicle. I must say our GP and assistant went above and beyond the call of duty as it was a freezing cold day with showers passing overhead occasionally, there wasn't even a gazebo where they could take some shelter, just the boot of a car where all the flu jabs and equipment were stored..." (791822)

5.1.2 Compassionate Care

Linked to the PCE standards authors of stories reflected upon the compassion of staff within Primary Care, reinforcing the value of listening to concerns and demonstrating empathy with authors highlighting how staff went "the extra mile" to support them.

"...My GP Practice XXXXX and the whole team from receptionists to practice nurses. Their kindness and compassion from the first phone call with the receptionists was audible and promptly followed up with GP contact either receiving advice on the phone or an appointment. Follow up calls were even received from XXXX and XXXXX on our progress on separate occasions. I truly was overwhelmed with their care and support even within these very busy and stressful times for them they took the time to show they care. I cannot thank them enough and want them to know what a fabulous job they are all doing and we are truly blessed to have this team working in our community..." (824287)

"...I recently had a phone call from City Hospital Belfast regarding a follow up appointment to discuss biopsy results. As the treatment had been in the Southern Trust I was naturally very concerned. June, the receptionist was extremely helpful and did her best to try and get me more information. She went to great lengths to reassure me and to arrange for my GP to call me back. All this at 3pm on a Friday afternoon. Overall the standard of care in XXXXX Health Centre is second to none..." (866112)

5.1.3 Efficient service

Stories with a positive experience, which refer to efficient services reflect upon:

- (a) Accessibility
- (b) Timely Communication and effective organisation
- (c) Collaborative working

The following quotes further expand upon and illustrate what matters most to the authors of the stories in relation to efficiency.

a- Accessibility

Stories include positive reflections on the patient's experience of contacting the GP surgery, communication and accessing care through the GP surgery. This also includes positive reflections on responsiveness for patients in an emergency and require temporary registration.

"...Both prior to and throughout the covid-19 pandemic I have required a GP service for myself or my family on a number of occasions, the GPs, nurses and reception staff working in this practice have been fabulous. We have always received the care we need, via telephone consultation or face to face if required. The staff team are professional, kind and caring..." (866037)

"...My GP rang back the same day and arranged to see me. She organised a red flag referral to the breast clinic at my local hospital, I am so grateful for her prompt care and attention..." (837696)

"...Mum had moved into my house on the day of diagnosis as she lived on her own too far away to travel for treatment and appointments. My GPs Dr XXXXX and Partners took over her care temporarily until she decided what would happen after treatment. They were fantastic and provided scripts as required to ensure mum got all her medications as prescribed..." (809460)

"...During a recent trip "home" to my native Belfast, my 22 month old son became unwell with what transpired to be a viral wheeze. I would like to thank all staff involved in his care. XXXXX Practice were absolutely brilliant, the process of getting my son registered as a temporary resident was so slick, easing our anxieties about accessing the care my son needed. Dr XXXXX who assessed him by telephone and in person was wonderful, she persevered and was understanding when my distressed son screamed all the way through the appointment... (866036)

b- Timely communication & effective organisation

An efficient service is closely linked to timely communication and effective organisation within positive experiences. This includes the processing of prescriptions, investigations, test results, treatment and advice. There is also reference to the multidisciplinary teams within Primary Care settings.

"...I have found the team at XXXXX medical centre to be so helpful anytime I need to get in contact. The Doctors are very responsive and I have always been able to get in touch with the surgery despite the pressures which a lot of GP surgeries have been under recently... In a time when GP's are getting a lot of criticism I just want to say thank you for your continuing care and that all your hard work is really appreciated..." (889109)

"...I forgot to commend the efficiency of my GP surgery for their help re thyroid blood tests, on-line prescriptions and general attitude when I need to use their services..." (820232)

"...Within a week of seeing the physiotherapist my mum had her knee x-rayed and the following day after the x-ray she was booked in for a pain relief injection the next week. She was delighted to be seen and treated so quickly as she had expected a long wait. Very efficient and professional service from start to finish..." (851834)

"...Very impressed with the First Contact Physiotherapy service in XXXXX Centre today. After a phone consultation with my GP he made me an appointment with the First Contact Physio and I was seen twice within days. The physio was friendly, efficient and gave clear advice. Great service..." (882624)

"...I needed clarification as to the changing of my medication and on contacting XXXXX Surgery I was reassured; advised and directed by a most excellent GP Pharmacist called Jacqueline who had the most ranging knowledge and expertise of not only the medication but of the medical condition that I was being treated for. A shining example of all that is good in the NHS..." (875995)

c- Collaborative working

Stories tagged as efficient also reflect upon collaborative working between teams within primary care and also the part primary care play in a patient's journey through to secondary care and care after discharge from hospital.

"...I would like to say a massive thank you to the ED team in CAH, our local GP surgery who have worked throughout this pandemic, the very helpful ambulance control and attending paramedics as well as the staff within the wards who cared for our 76 year-old Dad twice over the last month. Our family are extremely appreciative of all your efforts and having witnessed first-hand the extreme pressure you are under a thank you seems so inadequate but it's all we have. You are all doing your best within a system that often seems to be failing its staff but, yet one we would all be worse off without. We hope you all stay safe and thank you again for your all that you do..." (881684)

"...I was diagnosed with bowel cancer in the Summer of 2021. I went to see my GP who took bloods and then suggested that I do a stools FIT test. Within 2 weeks I was referred to the Endoscopy Unit to have a Colonoscopy... The GPs have been most compassionate and supportive. The North West Cancer Centre staff have also been very helpful and informative. In my eyes, to hear that the NHS is under-performing is nonsense. From seeing the GP at the beginning until having surgery, it only took 14 weeks..." (911903)

"...I went to see next available GP, who was Dr XXXXX with a lump in my breast... Since diagnosis and treatment 2 years ago, I have found all the staff at XXXXX Health Centre to be caring and professional at all times. Any concerns I have are always listened to and taken seriously... The treatment room nurses are always professional and efficient when I attend every 4 weeks for ongoing treatments, and the staff at the front desk are always helpful, and go out of their way to accommodate, which doesn't happen too often these days! I feel lucky to be registered with this practice..." (859869)

These themes are also echoed in the next section exploring what needs to improve reinforcing what matters most to the authors in the stories.

5.2 What could be Improved?

5.2.1 Communication

Communication is highlighted as one of the main areas for improvement. In the experiences shared the impact of lack of communication or miscommunication is apparent. Issues relate to contacting the GP practice by telephone and seeking results or follow up.

"...My GP practice has been getting work done on their phone system. Today I phoned to get results of a infection test. The phone went straight to prerecorded message telling me it was Tuesday and if I was phoning between 5. 30 and 6pm to phone another number. The number suggested was the same number as I had originally phoned and got the recorded message. I am an older person and I tried phoning the number... I normally do not complain but today I was left feeling annoyed, upset, anxious after a nurse told me I needed to have an examination to rule other things out. The GP was supposed to have phoned me and I never received a call. There were no missed calls on my phone. The Nurse said she

would leave a message for the GP to ring me before surgery was over and I got no call. I am asking for the GP practice to sort their phones so the public are not left in such a distressed state in future...” (831811)

“...I had met one amazing receptionist who was excellent in her role when I explained I was in a mental health crisis. This person offered support and explained who I could contact to escalate my concerns. Unfortunately, their colleagues did not demonstrate the same core values and if they had them, they have had ample opportunities to show them but failed. As new medication had been given and it started to settle I knew that I still needed medical help and that I wasn't ok yet, I had rang and asked for a call with the Dr or an appointment and was told to expect a phone call that phone call shortly after two- this never happened and when I rang again I was told that they had forgotten to put it on the list....” (837827)

“...Then we went back to A&E numerous times and one doctor told us to call our own GP be asked to put on the mini pill and referred by them to gynae. My doctor when I rang was annoyed that I was told to do this and said under no circumstances was she putting my child on a pill without a diagnosis as she was still being investigated. So we waited again on another consultant for another assessment...”(858970)

Within the returns there is one story with a criticality score of 4 which reflects upon communication between secondary care services and primary care services and highlights how this interface is crucial for continuity of care and informed decisions in relation to treatment and care. Unfortunately this story flags the consequences for patients and their families when the communication breaks down, mainly reflecting upon the emotional trauma experienced and lack of trust in the services involved.

“My family went through a living hell last year when my mum was told by her GP that she had lung cancer. I spoke to the doctor and she said it was terminal. My mum was given an appointment at Hospital three weeks later. We were distraught during this time and had even started to think about funeral arrangements. At that appointment my sister and I along with my mum expected to be given options for treatment, but the doctor we saw just said the scan showed up nodules that needed to be investigated. We would have to wait three months to see if they grew in size. We were dumbfounded as the word cancer never even came up in the conversation... so for the next three months was a roller-coaster of emotions, tears, sadness and a period of mourning.

We assumed the worst was to come given what the GP had said.; however when the follow-up appointment came around...we were told the nodules had shrunk. We were overjoyed and shocked at the same time. Our prayers had been answered. But we questioned why we were given a heart-breaking diagnosis in the first place? Did someone mess up?... The GP has never contacted us to apologise about the previous confusion. In fact when my mother went back to see the same GP she never even mentioned their previous diagnosis. This misdiagnosis and poor communication from the GP and Hospital in my opinion failed my mother and my family...It feels like our pain could have been avoided if individuals who dealt with my mum did their job right. I will never get over the trauma inflicted on my family...”

5.2.2 Challenges accessing appointments

Closely linked to communication is challenges authors detail in accessing appointments. Difficulty accessing the GP is detailed in 9 stories with concerns raised about referrals to Emergency Departments and delays in investigations or diagnosis.

“...When you ring the doctor surgery. You are say 5 in the queue.. you speak with reception who ask in detail the problems and then you are asked to ring back at given time or day to speak to a doctor. However, the receptionist is the advisor and you don't get to speak to a doctor and the receptionist suggests go to A&E... The doctors seem to have hidden since the pandemic...” (918661)

"...Unable to book an appointment to see a GP with pain in my shoulder. I finally got through to a receptionist who politely told me that no more appointments are available and I have to start phoning next Monday again. I have a brother who was diagnosed recently with multiple myeloma and his condition started in a similar way. However, my GP is my only path to getting the tests and having no access to them means no access to the tests. The lack of GP access will push people to seek treatment at the ED and will overwhelm that service. Some solution needs to be enacted before this leads to serious conditions not being treated or the death of individuals..." (865135)

"...I had spent three days trying to get through to my GP surgery, was able to see the GP who then sent me to XXXX A&E due to pelvic pain and numbness in my hip following surgery and a very high heart rate... As I said at the start, it's the system as a whole I find concerning. There doesn't seem to be a lot of continuity in the care. Referrals seem to take forever and waiting lists are huge, even before the added pressures of COVID..." (865341)

"...I feel that my elderly grandparent's care was very poorly managed by XXXXX (town name removed) Health Centre. A 6 hour wait in A&E that could have very easily been avoided if the practice could have accommodated a genuine complaint. I felt there was no patient centred care and it was a total waste of resources in the midst of a global pandemic. An elderly person with back pain and worsening mobility due to this that needed a pain review by their own GP to prevent this attendance and potential admission..." (859588)

5.2.3 Accessing services/treatment within Primary Care

There are a number of references to accessing mental health support and advice on gyane related matters through primary care. The stories highlight distress and frustration when seeking help in these areas and a move towards private sector; some of this is attributed to the impact of the pandemic.

"...Again told GP don't have the time to take out implants. Left GP surgery very distressed. The examination room had a broken window blind. I felt exposed and uncared for during the whole procedure. I have now booked to have my implant removed at Kingsbridge Private Hospital at a cost of £133. I am 22 years old and feel completely let down by my GP service in this matter..." (825436)

".... I questioned whether I should be on the pill aged 49 or not (having raised this on at least one occasion last year and being fobbed off), I was told I really should not be on the pill I am but another 2 months would be alright and to come back to them on it after that, I feel I have no choice but to seek a private consultation..." (922044)

"...Last March 2020 when this began my son's mental health support for self harm was cancelled. He was 12. My sons autism support was cancelled. He's at stage 3 of the education plan. My mental health support was cancelled. My face to face for diagnosis was cancelled. My mental health diagnosis support was cancelled. My gp would not see me for the whole of 2020 I had to pay private for a cancer biopsy..."

5.2.4 Lack of Compassionate Care

Within stories with a more negative experience (n=14) there is some reference to a lack of compassion and empathy within the experience. This includes very practical measures to support people when attending the surgery or recognising the patients distress.

"...Patients were required to wait outside (no marking for social distancing) for admittance by one of the admin staff. It was a particularly cold November morning and this is not appropriate for some elderly and vulnerable people. A one-way system had been put in place for the clinic - no chairs had been provided for those who were unable to stand for long periods and as a result the corridors was lined with people that were leaning against and touching windowsills and walls..." (837179)

"...I went for a routine blood pressure check in order to order a repeat pill prescription. I feel my issues relate to stress and anxiety caused by the recent death of my father (to who's funeral I could not attend) and the need to try and deal with his estate remotely, being amidst changing jobs and my mother having taken ill and needing to be placed in a

nursing home whilst suffering mental health issues. The GP's first question was - So when do you think this anxiety and stress will end..." (922044)

"...I was wearing a face covering, arrived on time and went in as the doors were open. This blocked the signage but I went inside and stopped to sanitise my hands. I was then abruptly told in no uncertain terms by a staff member of my mistake in entering the building. I felt their attitude was insulting and rude. I was embarrassed to be spoken to like this and felt humiliated in front of others. They sent me back outside and continued to give orders by gesturing and saying exactly I should stand on the pavement. I have no objection to standing outside but totally disagree with their attitude..." (805351)

"...My husband was seen by the doctor at XXXXX Health Centre regarding his worsening back pain and was advised to lose 2 5kg. My husband feels his pain was dismissed and is now reluctant to contact GPs. Poor practice, seems like the doctor went for the simplest answer without investigating cause. So dismissive and my husband is still in pain and now self-conscious regarding weight..." (927798)

6.0 NEXT STEPS


Care Opinion is currently available for patients, families and carers to share feedback on the whole Health and Social Care System including Primary Care. Care Opinion will continue to support the public to feedback on Primary Care, highlighting the positive work of the services and areas which need to improve. This briefing paper reflects the current feedback available on the Care Opinion system in the absence of promotion through Primary Care or bespoke campaigns.

Going forward consideration should be given to the benefits of specific campaigning within Primary Care to generate higher volume of stories in this area and support local and regional analysis and learning. Also, consideration should be given to capturing service user experience in light of strategic priorities for example, Intermediate Care, Enhanced Clinical Care Framework, No More Silos, and Multi-Disciplinary Teams in Primary Care.

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Question 3. "What are your feelings and emotions to your story"?



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