

# **Patients' Experiences**

## **Healthwatch Nottingham and Nottinghamshire**

### **Stage 1 Report**



**Nottingham Business School,  
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## Introduction and Background

Patient and public involvement in their health and social care became prominent following the Francis inquiry report into the Mid Staffordshire NHS Foundation Trust in 2013 (Francis 2013, Department of Health 2014). The government's response was a pledge to ensure that the leadership and management of the system would view the health and care system from patients' perspectives and to consider their views. Since the Francis report, patient and public involvement has been assumed as an inherent design feature of the NHS policy and delivery and is 'sewn-in' to achieving the triple aims of the NHS,<sup>1</sup> the development of Integrated Care Systems and the achievement of the NHS Long-Term Plan.

The notion of facilitating patient and public involvement is however not new. The first organisations, that actively encouraged the involvement of patients and the public in the of NHS were the Community Health Councils (CHCs) established in 1974. CHCs were established as independent bodies with powers to take up complaints from patients. Their ability to highlight poor practice in the health service embarrassed successive governments, although CHCs were also accused of very variable performance and impact. This led to their intended abolition under the NHS modernisation process of Alan Milburn when he was Secretary of State for Health (1999-2003). Controversy arose over plans in the 2001 Health and Social Care bill to give local councils greater scrutiny powers including the power to scrutinise the work of the NHS. The concern was that the patient advocacy and liaison service, outlined in the bill, could lack independence.

As a result, CHC's were abolished and a Commission for Patient and Public Involvement in Health (CPPIH) was established in January 2003 to set up and support new 'Patients' Forums' in order to 'monitor and review the operation of services provided by the trust; obtain the views of patients and their carers about those services and report on those views to the trust' (National Health Service Reform and Health Care Professions Act 2002, p20). However, their existence was short-lived and in 2007, evidence submitted to the Health Select Committee by the London Network of NHS Patients' Forums and others demonstrated the paucity of financial resources and opaque governance and management arrangements, and led to the abolition of the CPPIH as an independent, non-departmental public body (NDPB) on the 31st March 2008. In the interim, the 2007 Local Government and Public Involvement in Health Act, made provision for Patients' Forums to be replaced by Local Involvement Networks (LINKs) which extended patient and public involvement to social care provision funded by the local authorities, as well as to the NHS.

Unfortunately, as with their predecessors, the performance of LINKs was also very variable with only a minority being considered well-run and effective with Acute Hospital Trusts in particular not being as positive and engaged as envisaged. At this time the Coalition Governments' focus was on individualism and Health Secretary Andrew Lansley's interest in patient centred services was already developing in parallel with the Mid Staffordshire abuses

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<sup>1</sup> improving the quality of healthcare; improving the health of the population, and achieving value and financial sustainability

that resulted in the Francis Report (Francis 2013a). Francis made evident how the CHC, the PPIF and the local LINK were all unable to identify what was really going wrong in the Mid-Staffordshire Hospital, still less act effectively to stop it. Francis concluded that the arrangements for public and patient involvement, and for local government scrutiny in Stafford, were “a conspicuous failure” (See Francis 2013 (a) chapter 6, Patient and Public local involvement and scrutiny, pages 481-587).

As a result, the 2012 Health and Social Care Act replaced local LINKs with the Healthwatch system with the intention that the local Healthwatch acts as “the local consumer voice with a key role in influencing local commissioning decision” (Francis 2013b, page 47).

### Healthwatch England

Healthwatch England was established as the national body to provide leadership and support for the local Healthwatch network comprising 152 local Healthwatch organisations under the Health and Social Care Act 2012 (although a proposed regional tier of support and co-ordination was removed from the initial proposals). Yet again the intention was to strengthen public influence and provide an advocacy service and independent support as the patient and public champion for health and social care services (Department of Health and Social Care 2012). Healthwatch was established as an arms-length part of the Care Quality Commission and the CEO of Healthwatch England was a non-executive board member (Commissioner) of the CQC. Sir Robert Francis became Chair of Healthwatch England in October 2018 and is a board member of the Care Quality Commission.

### Local Healthwatch Organisations

Under the 2012 Act it is the local authorities’ statutory duty to commission the local Healthwatch organisation. They were intended to build on the previous functions of LINKs and have been commissioned to procure or contribute to a range of statutory activities such as designing local health and social care services. They do this by collecting patients’ and public’s ‘voices’, raising concerns to the providers and commissioners, monitoring, and inspecting the quality of the health and social care services, and writing reports and making recommendations for improving services locally. In contrast to LINKs, local Healthwatch organisations place greater focus on representing local communities, increase its profile through a commonly recognisable and unified entity and provide greater transparency and accountability (The Kings Fund 2015, Healthwatch 2020).

They play a much more extensive role in terms of influencing local decision-making process, i.e., influencing Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies. Local Healthwatch organisations have a seat on the local Health and Wellbeing Boards and are required to share information, such as reports, people’s specific concerns, feedback and other intelligence with the Care Quality Commission and Healthwatch England (Department of Health and Social Care 2012).

## Methodology

### Dataset

By listening to service users' needs and experience, Healthwatch Nottingham and Nottinghamshire (HWNN), helps people to raise issues with the services involved, in the hope of changing and improving local NHS and social care services. Working with HWNN, this stage of the project explored patient or public views collected by Healthwatch to-date to contribute developing 'Patient and Public Involvement in Integrated Care Systems in Nottingham and Nottinghamshire' as the second stage.

The dataset provided by HWNN contains queries, a combination of complaints, comments and questions raised by the patients and public from 2018 (August) to 2020 (August) in the area of Nottingham City and Nottinghamshire. The patients and public contacted HWNN regarding their experiences in using the health and social care services and, in response to the queries, HWNN assisted them to escalate their complaints to the relevant organisations, suggested ways to resolve the issues, or provided information and signposted for accessing the relevant services. HWNN in turn flagged up the concerns to local providers and commissioners.

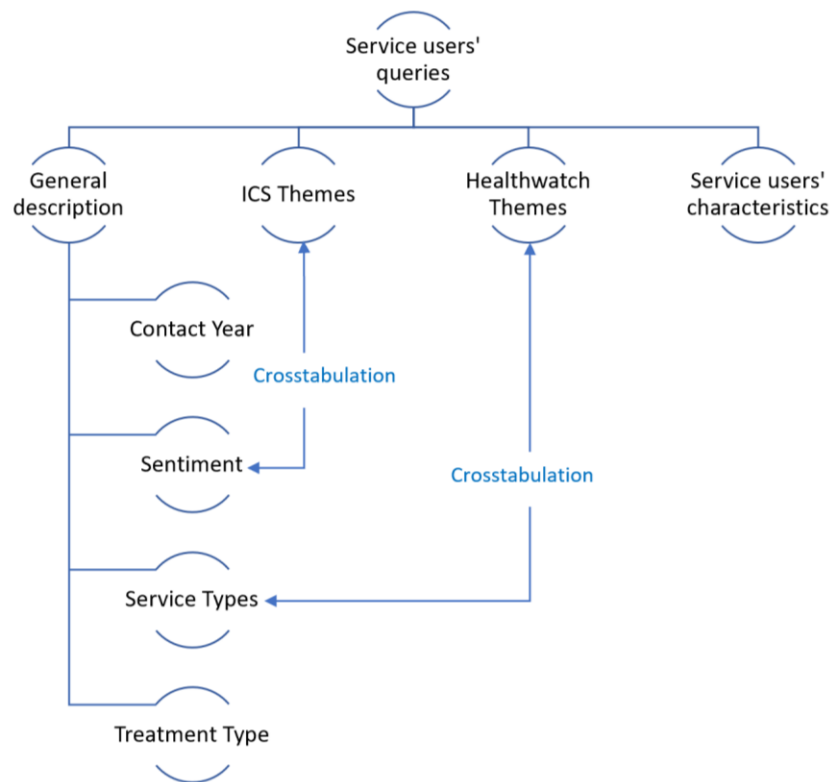
The analysis of the dataset was performed by examining the queries as:

- The general description of the queries: year of contact, sentiment, service type and treatment type
- Service users' health related characteristics
- Healthwatch defined themes cross tabulated with service types
- Themes related to Integrated Care System (ICS): *involvement in decisions, information, transition, medication and self-management, assessment and review, support and managing at home, care co-ordination, and co-ordination among teams.*

The analysis adopted the thematic coding method, wherein the service users' queries (texts) were coded into the themes related to ICS according to the content of the queries. It was anticipated that only a small number of cases could be coded into ICS related themes as, when service users contacted HWNN, the issue of ICS was not the reason why they contacted HWNN. Furthermore, the Healthwatch themes, pre-defined by the HWNN database were cross tabulated with the service type to gain more insight into the nature of the queries. The ICS themes were also cross tabulated with the sentiment (positive or negative) of the queries. The results of the analysis are presented as frequencies and percentages.

Diagram 1. below shows the layout of the data analysis.

Diagram 1: Data Analysis Layout



## Results

### General Description

Table 1: Year of Contact

Contact year	Frequency	Percent
2018	113	31.2
2019	207	57.2
2020	42	11.6
Total	362	100

Table 1 shows the number of contacts made by year. There were 362 cases in total. The year of contact is defined as the date when the use of the data was authorised. The majority of the contacts (57%) were made in 2019 as 2019 accounts for a full year's contacts while 2018 and 2020 only contain half year's contacts. 31% of the contacts were made in 2018 (from August) and only 11.6% (42 cases) in 2020 (August) when the COVID-19 pandemic occurred globally.

Table 2: Sentiment of the Queries

Sentiment	Frequency	Percent
	1	0.3
Negative	270	74.6
Positive	91	25.1
Total	362	100

The vast majority of the queries (74.6%) expressed negative sentiments concerning their health and social care.

Table 3: Queries by Service Type

Service type	Frequency	Percent
<b>Community Based</b>	<b>60</b>	<b>16.6</b>
Community Based - Day service	1	0.3
Dentists	25	6.9
Emergency Care	6	1.7
<b>GPs</b>	<b>121</b>	<b>33.4</b>
<b>Hospitals</b>	<b>87</b>	<b>24</b>
Mental Health	4	1.1
Mental Health - Community Based	10	2.8
Mental Health - Hospitals	5	1.4
Opticians	2	0.6
Other	10	2.8
Pharmacy	10	2.8
Social Care	6	1.7
Social Care - Care Home	11	3
Social Care - Children's Centre	1	0.3
Social Care - Home Care	2	0.6
Social Care - Supported Living	1	0.3
Total	362	100

From Table 3, one third (33.4%, the highest percentage) of the service users' queries were regarding their experiences in using General Practices (GPs), followed by Hospitals, the second highest percentage (24%) and Community-Based, the third highest percentage (16.6%).

To understand whether the result shown above reflect the general pattern of patient and public engagement, we examined the data regarding the hospital outpatient appointments and estimated GP appointments from the NHS Digital website.

Hospital outpatient appointments	<b>2017-18 (01 Apr 2017 to 31 Mar 2018)</b>	<b>2018-19 (01 Apr 2018 to 31 Mar 2019)</b>	Increase from previous year
	119.4 millions	123.4 millions	3.3%
GP appointments estimated to have happened	<b>2018 (between 01 Jan 2018 and 31 Dec 2018)</b>	<b>2019 (between 01 Jan 2019 and 31 Dec 2019)</b>	Increase from previous year
	308 millions	312 millions	1.3%
Data source: NHS Digital			

Although these two sets of data cover slightly different reporting periods (a calendar year for GP data and a business year for hospital data), the figures presented in table above demonstrate an increased rate for both numbers i.e., Hospital outpatient appointments and GP appointments estimated to have occurred between the two different years. The numbers of estimated GP appointments are more than double the numbers of Hospital outpatient appointments. Therefore, presumably, if there are more people making

appointments to see the GP service, it is likely that there would be more people making complaints or raising concerns about their experiences in using the respective services.

Breaking down the service users' queries further by treatment type, among 62 defined treatment types (full table in Appendix 1), the top five treatment types identified were as shown in Table 4. GP services accounted for one fifth of the queries, followed by the second highest percentage transport services (14.4%).

Table 4: Queries by Treatment Type (top 5)

Treatment type	Frequency	Percent
GP Services	74	20.4
Transport Services	52	14.4
Dental Services	26	7.2
Mental Health	20	5.5
Pharmacy Services	13	3.6

Moreover, the data analysis was carried out by exploring the Treatment type in different years to understand the trend of the patients' and public's queries (full table in Appendix 2).

Table 5: Treatment Type by Year (top 10)

2018	Frequency	Percent	2019	Frequency	Percent	2020	Frequency	Percent
Transport Services	46	40.7	GP Services	49	23.7	GP Services	6	14.3
GP Services	19	16.8	Dental Services	16	7.7	Unknown	6	14.3
Dental Services	9	8	Mental Health	13	6.3	A&E	3	7.1
Mental Health	5	4.4	Pharmacy Services	8	3.9	Care of the Elderly	2	4.8
Care of the Elderly	3	2.7	Diagnosis	7	3.4	Gastro and Intestinal Services	2	4.8
Outpatient Care	3	2.7	Ophthalmology	6	2.9	Mental Health	2	4.8
Pharmacy Services	3	2.7	A&E	5	2.4	Neurology	2	4.8
End of Life Care	2	1.8	Maternity	5	2.4	Pharmacy Services	2	4.8
GP Services - Practice Nurse	2	1.8	Orthopaedics	5	2.4	Respiratory Medicine	2	4.8
Oncology	2	1.8	Transport Services	5	2.4	ADHD	1	2.4
Total	113		Total	207		Total	47	

The results of the analysis shed some light on understanding the pattern of service users' queries overtime. GP Services remained as the top category when people contacted HWNN from 2018 (19 cases), 2019 (49 cases) to 2020 (6 cases). Similarly, Mental Health appeared in the top five treatment types mentioned by the service users throughout the years, followed by Pharmacy Services in the top ten.

Transport Services was the type with a significant fall from 2018 to 2020. There were 46 cases regarding Transport Services in 2018, then 5 cases in 2019 and only 1 case in 2020. Dental Services was the third highest type in 2018 and the second highest type in 2019. There was only 1 case regarding Dental Services in 2020 as people stopped going to the dental services due to the pandemic lockdown.

### Service Users' Health Related Characteristics

The following table introduces the health-related characteristics of the service users who contacted Healthwatch from 2018.



Table 6: Health-related Characteristics of the Service Users

	With long term illness/physical health		With a disability		With mental health issues		A carer	
	Frequency	Percent	Frequency	Percent	Frequency	Percent	Frequency	Percent
No	243	67.1	333	92	331	91.4	332	91.7
Yes	119	32.9	29	8	31	8.6	30	8.3

One third of the service users stated that they had a long-term illness or physical health condition, with a minority of them with a disability (8%) and with mental health issues (8.6%). 8.3% of them stated that they are a carer.

### Healthwatch Themes with Service Type

The nature of the service users' queries is mostly intertwined with multiple issues and inquires. Based on the contents of the service users' queries, HWNN categorised the information into 72 different themes to understand the genre of the queries (Appendix 2). One service user's query therefore could involve different themes at the same time. To gain further insight into people's needs and experience, a crosstabulation was performed to explore the themes (top six) in relation with the top three service types highlighted in Table 3.

Table 7: Healthwatch defined themes (top 6) crosstabulation with service types (top 3)

HealthWatch Themes	Total	% of total	GP	GP%	Hospital	Hospital%	Community Based	Community Based%
Staff - Communication - Negative	56	15.47	22	39.3	10	17.9		
Treatment and care - Effectiveness - Negative	39	10.77	14	35.9	11	28.2		
Treatment and care - Journey/Transport - Negative	37	10.22					34	91.9
Staff - Positive	36	9.94	6	16.7	4	11.1	22	61.1
Staff - Compassionate care - Negative	32	8.84	8	25.0	9	28.1		
Administration - Communication - Negative	31	8.56	12	38.7	7	22.6		

Six themes stand out from the analysis among all themes. 15.5% (the highest percentage) of the queries were related to *Staff Communication Negative*, followed by *Treatment and care Effectiveness Negative* (10.8%) and *Treatment and care Journey/Transport Negative* (10.2%). A positive sentiment, *Staff Positive* appeared as the fourth highest percentage (9.9%) among all. *Staff - Compassionate care – Negative* and *Administration - Communication – Negative* had a similar percentage.

When the top six themes were cross tabulated with top three service types (GP, Hospital and Community Based), it shows that within *Staff Communication Negative* category, more than one third was attributed to communications with staff of GP services and 18% was related hospital staff.

Within the GP service, the staff's poor communication often led to patients missing medication, missing appointments, cancelling appointments or re-arranging appointments, which caused a lot of confusion, exacerbated the situation, and resulted in hospitalisation for some service users. Some cases reported that the staff from the GP service were judgemental, using rude and unsympathetic language. They dismissed patients and made

them feel neglectful. This communication issue within the GP service were in line with the negative experience of communication between patients and staff within GP surgeries highlighted in the HWNN's report in 2019 (HWNN 2019 (b)). Similar experiences stated from the service users in this project were shared with the patients cited in the HWNN's 2019 for GP experiences.

Within the hospital service, staff's poor communication left elderly patients feeling helpless and unwell, and sometimes ended up hospital readmission. Some cases stated no explanation in what would happen next after discharge, no explanation in diagnosis and treatment, not enough time for questions and answers, and unsympathetic communication when delivering the results. The family members were also excluded from the communication.

Within the *Treatment and care Effectiveness Negative* category, over one third of the cases were attributable to the GP service, while one quarter of the cases were attributable to the hospital service.

Within the GP service, ineffective treatment and care resulted in problems persisting, inaccurate diagnoses, worsening patients' physical or mental health conditions, prolonging patients' pain condition and anxiety level. Sometimes, it led to hospital procedures. The hospital service cases reported problems such as patients being left in hospital bed without assistance or care, inaccurate diagnoses, negligence from the surgeon, and minor surgery leading to complex complications.

Within the *Treatment and care Journey/Transport Negative* category, an overwhelming number of the cases (92%) involved the community-based services being reported as insufficient. This was predominately about the outsourced transport service arrangements for pick-up and drop-off, which was said to be unreliable, late, absent, or badly equipped for people with a disability. This resulted in patients missing the hospital treatments and appointments.

Within the *Staff - Compassionate care – Negative* category, one quarter of the cases reported are attributable to the hospital service, while another quarter are attributable to the GP service. Some hospital staff were said to be rude, dismissed patients' needs for treatment, unsympathetic toward patients' health conditions, or made insensitive remarks about patients' health conditions. Patients felt that they were treated disrespectfully. Some staff from GP services were reported as not interested in listening to patients' needs, not understanding patients' physical health and mental health needs, making insensitive remarks about patients' conditions, and unwilling to show compassion and care.

Within the *Administration - Communication – Negative* category, nearly 40% of the cases are attributable to the GP service, while almost a quarter are attributable to the hospital service. For example, within the GP service, some patients stated that they were promised a phone call back from the surgery, but they did not receive one. It was difficult to make appointments or get registered with a GP. Appointments were cancelled without notification. The administration system and pharmacy failed to co-ordinate, leaving patients without medication. Within the hospital service, it is reported that the form filling and

record keeping were inadequate. There was also a lack of communication between departments and administration and therefore, the specialist was not aware of patients' needs and requirements. The administration was inefficient in making arrangements and considering the relevant logistics for patients with multiple needs.

However, within the *Staff Positive* category, 61% of the staff from Community-based services was reported as positive, followed by the staff from GP services (17%) and Hospital services (11%). An improving transport service from community-based services was the main reason for this positive feedback from the service users. This improving situation can be confirmed by the results from Table 5, which saw a sharp decrease in the number of Transport Services being raised as concern by the service users. They stated that the bus and taxi showed up on time and the drivers and crew were efficient, helpful, and friendly. This improvement in Transport Services was largely due to the change in new provider and new transport arrangements, such as *dedicated renal transport vehicle, reduced waiting time, and the introduction of the Renal Transport Coordinator* (HWNN 2015 and 2019a). Some staff from GP service and Hospital service was also described as compassionate, sympathetic, patient, and helpful.

### Integrated Care System related themes

The service users' queries were also thematically coded into relevant ICS themes to understand if people's needs and experiences were related to the issues regarding ICS. Similarly, one patient's query could contain several themes. The ICS themes are:

- *involvement in decisions,*
- *information, transition,*
- *medication and self-management,*
- *assessment and review,*
- *support and managing at home,*
- *care co-ordination, and*
- *co-ordination among teams.*

Not surprisingly, not all queries can be related to ICS themes and, overall, only about 10% of the queries (out of 362) can be linked with the ICS themes. The following sections provide the detailed of the analysis of the queries linked to the individual ICS themes.

### Theme 1: Involvement in decisions

Table 8: Involvement in Decisions

Sentiment	Involvement in decision in care and treatment	%	Involvement of a family member or someone else close	%
Positive	4	1.1	1	0.3
Negative	24	6.6	13	3.6
Total	362		362	

Few cases could be related to this theme. Among the cases, mostly expressed as negative, 24 of the service users did not feel that they were involved in decision in their care and treatment. They felt that their opinions about what treatment and care they preferred, and their needs did not matter to the professionals. A sense of frustration was expressed as their physical health and mental health conditions failed to progress. 13 cases reported that a family member or someone else close to them were not involved in the decisions on treatment and care, especially for older people with multiple or complicated health conditions, people with mental health conditions, or children with special needs. This caused worries for their loved ones as some of these patients were unable to make decisions for themselves.

The issue of shared decision making among health professionals and patients was also addressed in HWNN’s 2019 focus group report. Similar narratives were mentioned in the report, such as *‘not having the confidence to question health professionals’*, *‘not being given personal choice’*, *‘not being presented with choices’*, *‘not understanding health professionals’*, and *‘not having friends, relatives or an advocate accompanying them’* (HWNN 2019c).

**Theme 2: Information**

Table 9: Information

Sentiment	Making sense of the information	%	Information available for decision making	%	Communications meet my needs (different formats/ interpreters/ special needs)	%	Accessibility of the information or medical records	%
Positive			7	1.9	1	0.3	1	0.3
Negative	8	2.2	25	6.9	2	0.6	5	1.4
Total	362		362		362		362	

Among the cases related to *Information*, 8 stated that it was not easy to make sense of the information being given (the length of assessment related information) or the information somehow caused confusion (mostly regarding the options for dental treatment).

25 of the cases were of the view that the information for decision making in their care and treatment was not easily available, such as for pain management, diagnosis, condition of the illness, or dental treatment.

There were 7 who expressed the positive side of the availability of the information. 1 case reported that the hospital staff was accommodating of her needs as English was her second language and took time to explain her condition and the treatment to her. 2 cases stated that their special needs (dyslexia, autism) for different forms of communication were ignored by the staff from the GP services.

5 of the cases stated the difficulty of accessing medical information or medical records when they requested for making decisions.

**Theme 3: Transitions**

Table 10: Transitions

Sentiment	Continuity of care	%	A plan in place after discharge	%
Positive	10	2.8	2	0.6
Negative	8	2.2	8	2.2
Total	362		362	

Among the cases related to *Transitions*, 10 stated that there was a continuity of care in getting support from social care, their health centre, or GP after discharge or moving between services, while 8 expressed the opposite. In 8 cases (some with multiple health conditions) patients mentioned that a plan was not in place after a major surgery, or care was not ready after discharge, leaving them feeling unsupported and not knowing what to do next. In few cases, the service users did not feel well enough to be discharged or were readmitted to hospital few days later.

#### Theme 4: Medication and Self-management

Table 11: Medication and Self-management

Sentiment	Explanation of the medication	%	Involvement in decision about medication	%	Review of the medication	%
Positive	1	0.3			1	0.3
Negative	2	0.6	12	3.3	5	1.4
Total	362		362		362	

It is worth noting that 12 cases reported no involvement in decisions about medication. For example, they described that their views were not being listened to regarding the severe side effect of certain medicine, an allergic reaction from taking certain medicine, or the ineffectiveness of the medicine given. 5 cases stated that there were either problems after reviewing the medicine (in getting the new medicine or the availability of the medicine) or there was no review after being given a new medicine.

#### Theme 5: Assessment - Planning care and Reviewing care plans

Table 12: Assessment - Planning care and Reviewing care plans

Sentiment	Review of the medical history	%	Follow-up and review of the treatment	%	Care and treatment plan taking into account personal circumstances	%	Assessment and review	%
Positive	1	0.3	6	1.7	4	1.1	8	2.2
Negative			10	2.8	3	0.8	7	1.9
Total	362		362		362		362	

Among the cases related to *Assessment*, 10 cases reported that there was no follow-up and review to see if the treatment worked for the patients. However, 8 cases report a positive situation of assessment of treatment and care and regular review of the care plan. 4 reported that their care and treatment plan took into account their personal circumstances, such as home environment, family situation, physical condition, or mental condition.

## Theme 6: Support for Managing at home

Table 13: Support for Managing at home

Sentiment	Care and support help to live the quality of life	%	Support for self-care	%	Emergency care or out of hours care available	%	Support by group activities	%
Positive	5	1.4	8	2.2	13	3.6	6	1.7
Negative	10	2.8	7	1.9	6	1.7	1	0.3
Total	362		362		362		362	

For the cases that could be related to theme 6, 10 expressed the view that care and support were not sufficiently available to help them live a quality life, such as the financial support required for home adaptation (wet room, ramp for wheelchair access, and stairlift), pain management for severe pain, and support for their mental condition. 5 reported unexpected stays in hospital due to the lack of timely treatment and care from GP and care home.

Some positive aspects were also reported by the service users. 8 cases stated that they had support for self-care at home, such as knowing whom to contact if there was a problem or concern; medicine made ready to enable them manage at home; apps, technology, equipment and aids available to help them at home; rehabilitation and physiotherapy in place to support them.

13 reported positive sentiments with regards to the availability of emergency care and out of hours care in emergency appointments offered by GP, GP out of hours home visit, 111 service, and ambulance service. 6 stated that they were supported by group activities, such as day service activities for Parkinson, Dementia, Autism, cancer patients, exercise class for macular degeneration and post-natal group. By participating in these group activities, they interacted with other patients or parents with similar situations; they engaged in fun activities and received advice about the diet for managing diabetes and their confidence, social ability and mobility levels were improved.

## Theme 7: Care co-ordination

Table 14: Care co-ordination

Sentiment	Multi-agency or multi-disciplinary team	%	The professionals aware of other health conditions	%	Clarity of the care co-ordination	%
Positive	19	5.2	3	0.8	3	0.8
Negative	15	4.1	16	4.4	12	3.3
Total	362		362		362	

Under the theme of *Care co-ordination*, 19 cases reported a positive outcome for multi-agency or multi-disciplinary teams working well together in hospitals, GP surgeries or Community based services. For example, within hospitals, the ambulance service, Accident and Emergency, radiology, surgery (surgical procedure), anaesthesiology and the stroke unit co-ordinated well together. Within GP surgeries, doctors, nurses, pharmacies, and physios worked well together. So too did the maternity unit, health visit centre and children centre within Community based services.

However, 16 stated that the professionals were not aware of service users' other health conditions. For example, service users expressed that when they went to see their GPs (13 cases); got treated in the hospital (1 case); stayed in the hospital (1 case) or saw a dentist (1 case), the professionals were likely to focus the diagnosis on their acute conditions (the reasons why the patients were being seen) rather than to link with patients' other health needs to treat them holistically, especially for patients with multiple health conditions either physically or mentally. 12 cases reported that there was a lack of clarity of the care co-ordination among care homes, social services, hospitals, GPs, other community-based services and their own families, especially for people with multiple long term health or mental conditions, leaving them with a sense of confusion and helplessness.

### Theme 8: Co-ordination among teams

Table 15: Co-ordination among teams

Sentiment	Timely referral	%	Timely response or action from other services	%	The professionals involved work as a team (joined up working)	%	Patients' records (information) were shared among different teams	%
Positive	30	8.3	15	4.1	8	2.2	2	0.6
Negative	16	4.4	16	4.4	22	6.1	17	4.7
Total	362		362		362		362	

More cases can be related to ICS theme 7 from the dataset. The positive side of the reporting is that referrals were made timely from GPs, dentists, opticians, and the hospital to the relevant services. However, the referrals did not guarantee timely responses or actions from other services for care or treatment, and this is in line with the result of 16 negative cases. Moreover, there are more negative cases (22) for joined up working among the professionals. Often patients expressed the view that doctors (meaning GPs and hospital doctors) said different things (contradiction) or that patients got 'pushed' between different professionals (doctors, dentists, and opticians) as well as within social care (care home and social workers). There was little or no communication amongst different professionals. This corresponds to the situation of more negative views about the clarity of care co-ordination. 17 cases reported that patients' records or information were not shared among different teams, which resulted in patients repeating their medical history to different professionals, or the professionals were not aware of patients' past treatment, and in some cases led to ineffective treatment or unnecessary surgical procedures.

### **Discussion**

Before moving on to the discussion of the findings, it is important to be aware of the limitation of drawing any detailed or general conclusions from this local situation or the results presented in this report as the database and the numbers available are so small and cannot be representative. However, by examining the qualitative (text-based) data, it can reveal and some insights that might help lead to more in-depth understanding of service users' views and experiences from using health and social care services. This exploration

can be beneficial as the information provides a useful insight into the development of indicators for the new ICS and ultimately the re-design of healthcare services.

The results shown in this report demonstrate that the COVID-19 pandemic has had an impact on patients' and public's use of health and social care services, and this has led to a decrease in the number of people contacted HWNN with concerns in 2020. Moreover, the new business plan 2020-2023 of HWNN outlines an approach to move away from collecting general patients' experiences to focusing instead on significant issues, which also has a significant impact on the volume of patients' experiences collected. However, it is vital that patients' and public's views are listened to and they are encouraged to give feedback regarding their experiences in using the services so that the services can be improved and designed to put people first in the centre of the health and social care services. In turn, this will help HWNN to continue playing a role as an advocate for patients and the public to influence the local decision-making process (Francis 2020).

The current findings also indicate where patients' and public's needs stem from. They are spread across and mostly concerned around

- the primary care (the GP services, dental services, pharmacy services),
- secondary care primarily hospital services,
- community-based services and
- mental health issues.

Particularly, poor communication and a lack of compassionate care from staff in GP and hospital services are relatively tangible, capable of improvement and the outcome of potential improvements could possibly result in a better treatment and care for patients. Poor communication and the lack of compassionate care are evident from the narratives of the patients' and public's contributions, and these were often accompanied by patients' deteriorating physical or mental health conditions.

An improvement in transportation services is evident from the in-depth analysis of the trend overtime. The interventions, such as change of the new transport provider and some new transport service arrangements have been put in place to improve the service are likely to be the reasons for the improvement. Further research into how the new provider operates differently could be investigated as a potential good practice for dissemination to other community-based services

### Integrated Care Services

As there is only a limited number of cases related to Integrated Care Services (around 10% out of 362 cases), the overall pattern of results reflects the more segregated aspects of the health and social care services rather than the integrated aspects of services. In summary:

*Involvement in decisions* – There is some evidence that patients (24 cases) and their family members and/or someone close to them (13 cases) did not feel that they were as involved in decisions about their treatment and care as they would have wished.



*Information* – Similarly, patients (8 cases) felt that they were left alone to make sense of the information they received, and 25 cases reported that the information was not available for them to make decision regarding their treatment and care. 5 cases reported the needs for accessing medical information and records and 2 cases were related to the requirement for different forms of communication for people with special education needs.

*Transition* – a situation of continuity of care and getting support from social care, the health centre or GP after discharge or moving between services was mentioned by 10 service users. However, 8 service users reported that there was no plan in place after discharge leaving them feeling unsupported.

*Medication and self-management* – Lack of involvement in decisions about medication was highlighted by 12 patients with 5 other cases concerned about the reviewing of the medication and explanation of the medication (2 cases).

*Assessment and review* – 10 cases reported no followed up review of treatment. However, 8 cases reported that the assessment for care or treatment plan and regular review of the plan were implemented. 3 service users mentioned that their personal circumstances were taken into account in their plans for care and treatment.

*Support and managing at home* – Generally, it was reported that there was insufficient care and support available to help patients to live a quality life (10 cases) or help them to care for themselves (7 cases) after discharge from treatment. However, 13 cases reported that the emergency care or out of hours care was available when they needed it. There was some support offered by the group activities (6 cases) to help them manage their conditions, such as for Parkinson, Dementia, Autism, cancer, macular degeneration, and post-natal care. These group activities helped them to improve their confidence, social ability, and mobility levels by interacting with other patients or parents with similar situations, engaging in fun activities, and getting advice about the diet for managing diabetes.

*Care co-ordination* – 19 service users reported the positive situation for multi-agency or multi-disciplinary teams working well together in hospitals, GP surgeries or Community based services. However, 16 service users felt that the health professionals, especially GPs (13 cases) were not aware of their other health conditions. There was a lack of clarity in the care co-ordination too (12 cases reported).

*Co-ordination among teams* - More cases (30 cases) reported that the referrals were made timely but the response or action from other services did not mirror these patients' needs for prompt treatment and care (16 cases reported). There was no joined up working among the professionals involved (22 cases) and patients' records or information did not appear to be shared among different teams (17 cases).

As we are looking to develop metrics that may be appropriate for Integrated Care Systems the responses to theme 7 and 8 are particularly interesting.

It is unfortunate (but maybe not a surprise) that only a small number of cases can be related to ICS themes from the dataset. This reinforces the need for the development of a new "integration index" as the performance measures of integrated care system mentioned in

the NHS Long Term Plan 2019. This integration index will need to be designed with the involvement of patient groups and the voluntary sector, which measures the success of ICS from patient's, carers and the public's perspectives so that a true patient-centred integrated care system can be achieved. Moreover, the limited implication of the result also highlights that further research is urgently needed to understand what integrated care system means to the service users and what their experiences are likely to be when engaged with the integrated care system.

Finally, if the paucity of information that is available for developing ICS key indicators in Nottingham and Nottinghamshire is a characteristic of all parts of the country, it helps us to understand why the development of ICS indicators was (apparently) abruptly terminated.

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## Appendix 1: Treatment Type

Treatment type	Frequency	Percent
	4	1.1
A&E	8	2.2
ADHD	1	0.3
Admission	3	0.8
Audiology	2	0.6
Autism	3	0.8
Cancer Services	4	1.1
Cardiology	2	0.6
Care at Home	3	0.8
Care of Children	4	1.1
Care of the Elderly	7	1.9
Chiropody	2	0.6
Community Nursing	3	0.8
Consultation	1	0.3
Continuing Healthcare	1	0.3
Day Surgery	3	0.8
Dementia	3	0.8
<b>Dental Services</b>	<b>26</b>	<b>7.2</b>
Dental Services - Specialist	1	0.3
Dermatology	3	0.8
Diabetic Medecine	2	0.6
Diagnosis	8	2.2
Discharge	1	0.3
Discharge to Assess	2	0.6
End of Life Care	3	0.8
Endocrinology	1	0.3
ENT	2	0.6
Fall Injury	3	0.8
Gastro and Intestinal Services	2	0.6
<b>GP Services</b>	<b>74</b>	<b>20.4</b>
GP Services - Practice Nurse	2	0.6
Haematology	1	0.3
Imaging (inc. MRI & Radiology)	2	0.6
Maternity	6	1.7
<b>Mental Health</b>	<b>20</b>	<b>5.5</b>
Mental Health - CRISIS Line	2	0.6
Muscular Skeletal	2	0.6
Nephrology (Renal)	1	0.3
Neurology	3	0.8
Occupational Therapy	1	0.3
Oncology	4	1.1
Ophthalmology	8	2.2
Orthopaedics	6	1.7
Outpatient Care	7	1.9
Paediatric Services	1	0.3
Pain Management	3	0.8
<b>Pharmacy Services</b>	<b>13</b>	<b>3.6</b>
Phlebotomy	5	1.4
Physiotherapy	6	1.7
Podiatry	2	0.6
Prescription/Purchase of Medical Supplies	1	0.3
Psychiatry	1	0.3
Purchase of Medical Supplies	4	1.1
Respiratory Medicine	3	0.8
Rheumatolgy	2	0.6
Spinal Injury	3	0.8
Stroke Services	4	1.1
Surgery	2	0.6
<b>Transport Services</b>	<b>52</b>	<b>14.4</b>
Treatment at Home	1	0.3
Unknown	7	1.9
Urology	2	0.6
Visitation	3	0.8
<b>Total</b>	<b>362</b>	<b>100</b>

## Appendix 2: Treatment type by year

2018	Frequency	Percent	2019	Frequency	Percent	2020	Frequency	Percent
Transport Services	46	40.7	GP Services	49	23.7	GP Services	6	14.3
GP Services	19	16.8	Dental Services	16	7.7	Unknown	6	14.3
Dental Services	9	8	Mental Health	13	6.3	A&E	3	7.1
Mental Health	5	4.4	Pharmacy Services	8	3.9	Care of the Elderly	2	4.8
Care of the Elderly	3	2.7	Diagnosis	7	3.4	Gastro and Intestinal S	2	4.8
Outpatient Care	3	2.7	Ophthalmology	6	2.9	Mental Health	2	4.8
Pharmacy Services	3	2.7	A&E	5	2.4	Neurology	2	4.8
End of Life Care	2	1.8	Maternity	5	2.4	Pharmacy Services	2	4.8
GP Services - Practice Nurse	2	1.8	Orthopaedics	5	2.4	Respiratory Medicine	2	4.8
Oncology	2	1.8	Transport Services	5	2.4	ADHD	1	2.4
Ophthalmology	2	1.8	Unknown	5	2.4	Cancer Services	1	2.4
Physiotherapy	2	1.8	Outpatient Care	4	1.9	Community Nursing	1	2.4
Purchase of Medical Supplies	2	1.8	Phlebotomy	4	1.9	Dental Services	1	2.4
Admission	1	0.9	Autism	3	1.4	Dermatology	1	2.4
Care at Home	1	0.9	Cancer Services	3	1.4	Diagnosis	1	2.4
Care of Children	1	0.9	Care of Children	3	1.4	End of Life Care	1	2.4
Chiropody	1	0.9	Fall Injury	3	1.4	Maternity	1	2.4
Day Surgery	1	0.9	Physiotherapy	3	1.4	Orthopaedics	1	2.4
Dementia	1	0.9	Spinal Injury	3	1.4	Phlebotomy	1	2.4
Dental Services - Specialist	1	0.9	Stroke Services	3	1.4	Physiotherapy	1	2.4
Dermatology	1	0.9	Visitation	3	1.4	Podiatry	1	2.4
Discharge to Assess	1	0.9	Admission	2	1	Prescription/Purchase of	1	2.4
Mental Health - CRISIS Line	1	0.9	Audiology	2	1	Psychiatry	1	2.4
Pain Management	1	0.9	Cardiology	2	1	Transport Services	1	2.4
Rheumatology	1	0.9	Care at Home	2	1	Total	42	100
Stroke Services	1	0.9	Care of the Elderly	2	1			
Total	113	100	Community Nursing	2	1			
			Day Surgery	2	1			
			Dementia	2	1			
			Diabetic Medecine	2	1			
			ENT	2	1			
			Imaging (inc. MRI & Rad	2	1			
			Muscular Skeletal	2	1			
			Oncology	2	1			
			Pain Management	2	1			
			Purchase of Medical Su	2	1			
			Surgery	2	1			
			Urology	2	1			
			Chiropody	1	0.5			
			Consultation	1	0.5			
			Continuing Healthcare	1	0.5			
			Dermatology	1	0.5			
			Discharge	1	0.5			
			Discharge to Assess	1	0.5			
			Endocrinology	1	0.5			
			Haematology	1	0.5			
			Mental Health - CRISIS	1	0.5			
			Nephrology (Renal)	1	0.5			
			Neurology	1	0.5			
			Occupational Therapy	1	0.5			
			Paediatric Services	1	0.5			
			Podiatry	1	0.5			
			Respiratory Medicine	1	0.5			
			Rheumatology	1	0.5			
			Treatment at Home	1	0.5			
			Total	207	100			

### Appendix 3: Themes from Healthwatch

HealthWatch Themes	Total	% of total
Staff - Communication - Negative	56	15.47
Treatment and care - Effectiveness - Negative	39	10.77
Treatment and care - Journey/Transport - Negative	37	10.22
Staff - Positive	36	9.94
Staff - Compassionate care - Negative	32	8.84
Administration - Communication - Negative	31	8.56
Treatment and care - Medication - Negative	27	7.46
Treatment and care - Practices - Negative	25	6.91
Access to services - Waiting times - Negative	24	6.63
Administration - Management of service - Negative	24	6.63
Diagnosis/assessment - Negative	23	6.35
Treatment and care - Effectiveness - Positive	22	6.08
Staff - Compassionate care - Positive	20	5.52
Access to services - Convenience - Negative	18	4.97
Making a complaint - Negative	18	4.97
Treatment and care - Unspecified - Positive	18	4.97
Access to services - Negative	17	4.70
Diagnosis/assessment - Mis-diagnosis/assessment - Negative	17	4.70
Staff - Communication - Positive	17	4.70
Staff - Professional manner - Negative	17	4.70
Access to services - Lack of - Negative	16	4.42
Access to services - Appointment availability - Negative	14	3.87
Access to services - Positive	14	3.87
Staff - Negative	13	3.59
Treatment and care - Dignity and respect - Negative	13	3.59
Administration - Medical records - Negative	12	3.31
Treatment and care - Waiting times - Negative	12	3.31
Access to services - Appointment convenience - Negative	11	3.04
Access to services - Convenience - Positive	11	3.04
Access to services - Waiting times - Positive	11	3.04
Treatment and care - Journey/Transport - Positive	10	2.76
Treatment and care - Unspecified - Negative	10	2.76
Access to services - Inequality - Negative	9	2.49
Diagnosis/assessment - Lack of - Negative	9	2.49
Diagnosis/assessment - Positive	9	2.49
Treatment and care - Patient choice - Negative	8	2.21
Treatment and care - Practices - Positive	8	2.21
Access to services - Patient choice - Negative	7	1.93
Staff - Capacity - Negative	7	1.93
Discharge - Speed - Negative	6	1.66
Treatment and care - Medication - Positive	6	1.66
Access to services - Appointment availability - Positive	5	1.38
Access to services - Safety - Negative	5	1.38
Access to services - Unspecified - Positive	5	1.38
Administration - Staff - Negative	5	1.38
Facilities and surroundings - Food and drink - Negative	5	1.38
Treatment and care - Waiting times - Positive	5	1.38
Access to services - Unspecified - Negative	4	1.10
Administration - Communication - Positive	4	1.10
Administration - Management of service - Positive	4	1.10
Diagnosis/assessment - Late - Negative	4	1.10
Discharge - Preparation - Negative	4	1.10
Non-specific - Intelligence - Negative	4	1.10
Staff - Professional manner - Positive	4	1.10
Treatment and care - Dignity and respect - Positive	4	1.10
Access to services - Appointment convenience - Positive	3	0.83
Access to services - Unable to contact service - Negative	3	0.83
Administration - Negative	3	0.83
Discharge - Negative	3	0.83
Facilities and surroundings - Car parking - Negative	3	0.83
Referrals - Negative	3	0.83
Staff - Capacity - Positive	3	0.83
Staff - Training and development - Negative	3	0.83
Digital Services - Access to - Negative	2	0.55
Discharge - Safety - Negative	2	0.55
Facilities and surroundings - Food and drink - Positive	2	0.55
Facilities and surroundings - Transport links - Negative	2	0.55
Facilities and surroundings - Transport links - Positive	2	0.55
Referrals - Waiting times - Negative	2	0.55
Staff - Unspecified - Negative	2	0.55
Access to services - Location - Negative	1	0.28
Access to services - Location - Positive	1	0.28
	362	100