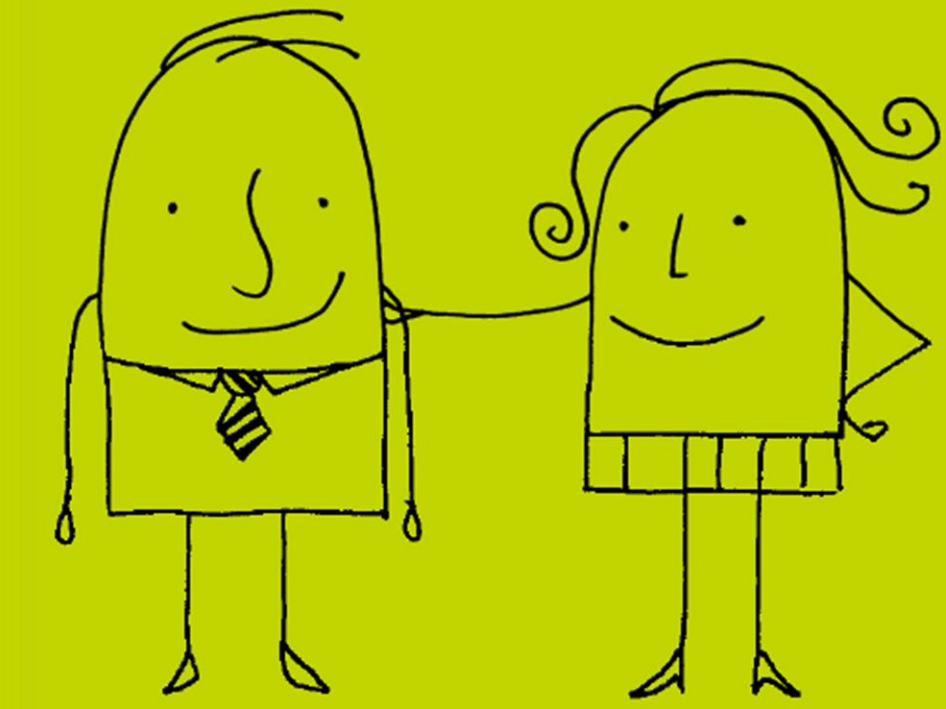
Patient and Client Council
Your voice in health and social care

Peoples' Priorities

March 2021

Published to website August 2022



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List of Abbreviations

Acronym	Meaning
PCC	Patient and Client Council
HSC	Health & Social Care
MS	Microsoft
BHSCT	Belfast Health & Social Care Trust
WHSCT	Western Health & Social Care Trust
SEHSCT	South Eastern Health & Social Care Trust
SHSCT	Southern Health & Social Care Trust
NHSCT	Northern Health & Social Care Trust
GP	General Practitioner
NHS	National Health Service
VCSE	Voluntary, Community & Social Enterprise
NI	Northern Ireland
DoH	Department of Health
PINNT	Patients on Intravenous and Nasogastric Nutrition
AMH	Action Mental Health
PHA	Public Health Agency
CPN	Community Psychiatric Nurse
UK	United Kingdom
PPE	Personal Protective Equipment
BMA	British Medical Association
GMC	General Medical Council
SARS	Severe Acute Respiratory Syndrome
PTSD	Post-Traumatic Stress Disorder
A&E	Accident and Emergency
RCGPNI	Royal College of General Practitioners Northern Ireland

1. Introduction

1.1 Background

The PCC was established by the Health and Social Care (Reform) Act (NI) 2009 to ensure that the 'voice of patients, clients, carers and communities is valued, heard and acted upon' in the development of policy on, and provision of, Health and Social Care (HSC) services. This statutory role gives the PCC a unique place within the HSC sector in Northern Ireland.

The findings of this report were gathered during the period December 2020- March 2021 and as such, reflect the feedback from the public at this particular point in time. It should be noted that during this period, the COVID-19 pandemic was impacting the way in which we went about our daily business and accessed services.

That COVID-19 has had an impact on HSC services is not disputed; understanding how the public experienced this impact on services is the subject of this report. At this time not only of major change, but of unprecedented and unexpected pressures on the whole HSC system, it is vital to maintain focus on listening to, and respecting the voices of, patients and service users; and on ensuring that resources are deployed to the best effect possible.

The purpose of this report was to capture the experience of the public of HSC services during COVID-19, and to capture the impact they felt COVID-19 had on the services they received. It reflects what respondents told us. It is intended that this report will inform policy makers, generate conversation, grow networks and highlight systems which do not serve the public. This paper is influenced by recently published HSC reports; Systems not Structures[1], Power to the People[2], Delivering Together[3] and A New Decade a New Approach[4].

[1] Department of Health. *Systems, Not Structures - Changing Health & Social Care. https://www.health-ni.gov.uk/sites/default/files/publications/health/expert-panel-full-report.pdf (accessed 6 May 2021).*
[2] Department of Health. *Power to People - Proposals to reboot adult care & support in NI. https://www.health-ni.gov.uk/sites/default/files/publications/health/power-to-people-full-report.PDF (accessed 6 May 2021).*
[3] Department of Health. *Health and Wellbeing 2026 - Delivering Together . https://www.health-ni.gov.uk/sites/default/files/publications/health/health-and-wellbeing-2026-delivering-together.pdf (accessed 6 May 2021).*
[4] NI Executive. *New Decade, New Approach . https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/856998/2020-01-08_a_new_decade__a_new_approach.pdf (accessed 6 May 2021).*

1.2 Aims and Objectives

The objectives of this work were to hear and understand:

- Peoples' experiences of using HSC services during the COVID-19 pandemic;
- The consequences of COVID-19 for peoples' routine / scheduled healthcare and social care.
- Peoples' levels of satisfaction with the restrictions imposed on 'normal' HSC services due to COVID-19; and
- The extent to which people feel that they have been adequately informed on how to keep themselves (and the wider population) safe and healthy.

2 Literature Review

A review of literature, internal and external, was conducted in order to inform the questions asked of the public and to frame the answers given.

2.1 Internal

PCC has a small Research Team who, throughout 2020, undertook various pieces of work to understand how the public experienced services during the pandemic.

2.1.1 Marie Curie; Grief & Bereavement during COVID-19.[5]

This piece of research looked at the impact of COVID-19 for those who lost a loved one between March 2020 and January 2021. Reference was made to the feeling of disconnect between HSC services. Respondents felt COVID-19 had impacted timely access to support, care, help and advice. Communication issues were raised in relation to PPE as well as the barriers created through a lack of face-to-face support. Social media was highlighted as a resource for not only information but also support.

2.1.2 Exploring the experiences and perspectives of clinically extremely vulnerable people during COVID-19 shielding[6]

The Shielding Survey and resulting report highlighted that ~1/3 of people wanted more, and better, information. We therefore asked in this Peoples' Priorities survey for additional detail in this area. The results evidenced that 27% of participants felt they'd endured a negative impact on their mental health & emotional wellbeing as a result of having to shield.

2.1.3 HSCB Remote Sign Language Interpreting Service[7]

We undertook a project to evaluate peoples' experience of the HSCB Remote Sign Language Interpreting Service from October 2020-March 2021. Concerns were raised in relation to the use of technology for communication and information provision e.g. GPs trying to contact service users via telephone. Fear of accessing HSC services was also expressed, with concerns specifically relating to being

[5] PCC (2021) *Marie Curie Bereavement, Grief and Palliative Care sessions*, PCC, Belfast.
[6] PCC (2020) *Exploring the experiences and perspectives of clinically extremely vulnerable people during COVID-19 shielding*, PCC, Belfast.
[7] PCC (2021) *Regional Communication Support Services: Remote Sign Language Interpreting Service*, PCC, Belfast.

exposed to COVID-19 when attending Emergency Departments, and also through HSC staff removing masks to try and communicate.

2.1.4 Client Support Dashboard Findings[8]

Throughout 2020-2021, the PCC has continued to deliver advocacy support for people with concerns about HSC under the additional pressures of the COVID-19 pandemic. During the year, the organisation has continued to develop its service to the public, including to patients, families and carers. The top five service areas that patients contacted PCC about were:

	Top 5 New Case Service Areas	New Cases 2020 / 2021	
1	GP	64	14.7%
2	MENTAL HEALTH	38	8.7%
3	RESIDENTIAL AND NURSING HOMES	33	7.6%
4	ELDERLY CARE	32	7.3%
5	FAMILY AND CHILDCARE	23	5.3%

The top five issues raised were:

- Treatment and care (50.5%)
- Communication (20.9%)
- Staff attitude (16.1%)
- Waiting times and cancellations (10.8%)
- Professional assessments of need (8.9%)

[8] PCC (2021) *Client Support Dashboard Findings*, PCC, Belfast.

Treatment and Care

Within the area of treatment and care, the issues raised can be further categorised as shown in the table below. Quality of treatment remains the most frequently cited area of concern.

Treatment and Care Subcategories	Formal complaint	Issue/concern	Total
Quality	82	22	**104**
Inappropriate Treatment	33	13	**46**
Diagnosis	29	7	**36**
Discharge	8	7	**15**
Nursing Care	6	4	**10**
Quantity	4	2	**6**
Surgery	4	0	**4**
Total	**166**	**55**	**221**

In tables in the next section outline figures relating to the themes of Communication, Staff Attitude, Waiting times and cancellations, and Professional Assessment of need. In each table we have shown the total number of issues raised within a particular category, along with the service areas to which the issue was most frequently cited as applicable.

Communication

Within the area of communication, the service area in which communication was most often cited as an issue was GPs, followed by Elderly Care, Residential and Nursing Homes, Mental Health and Family and Childcare.

Service Areas	Formal complaint	Issue / concern	Total
Communication Total	**56**	**35**	**91**
GP	6	6	12
ELDERLY CARE	6	4	10
RESIDENTIAL & NURSING HOMES	6	3	9
MENTAL HEALTH	5	3	8
FAMILY & CHILDCARE	5	2	7

Staff Attitude

Within the area of staff attitude, the service area most frequently cited was GPs and primary care, followed by Residential and Nursing Homes, Maternity, Hospital and A&E.

Service Areas	Formal complaint	Issue / concern	Total
Staff Attitude Total	**49**	**21**	**70**
GP	10	6	16
RESIDENTIAL & NURSING HOMES	3	3	6
MATERNITY	5	0	5
HOSPITAL	1	4	5
A&E	5	0	5

Waiting times, Delay and Cancellation

Almost as many formal complaints as issues were raised about wait times and cancelled treatments. The table below sets out the service areas these most frequently related to.

Service Areas	Formal complaint	Issue / concern	Total
Waiting Times/Delay/Cancellation	**24**	**23**	**47**
MENTAL HEALTH	3	4	7
ORTHOPAEDICS	4	1	5
UROLOGY	2	3	5
UNSPECIFIED	3	1	4
GP	0	4	4

Professional Assessment of Need

Almost twice as many formal complaints as issues were raised about assessment of need. The table below sets out the service areas these most frequently related to.

Service Areas	Formal complaint	Issue / concern	Total
Professional Assessment of Need	**25**	**14**	**39**
ELDERLY CARE	2	3	5
RESIDENTIAL & NURSING HOMES	3	1	4
MENTAL HEALTH	3	1	4
FAMILY & CHILDCARE	4	0	4
DISABILITY	2	1	3

PCC Freephone Service

Between 1/04/2020 and 1/04/2021, the PCC Freephone service received

- **6,195** total contacts, of which **3,637** (59%) related to COVID-19
- **2,192** (35.4%) contacts were referred to PCC by another organisation

Key themes included:

Theme(s) of contact	Number of contacts	% of total COVID-19 calls
Shielding / self-isolation	664	25.7%
Testing	595	23.0%
Work / employment	576	22.3%
Social distancing / social bubbles	286	11.1%
Travel	244	9.4%

2.1.5 Access to GP Services 2014[9]

Access to GP Services was a report issued by PCC in 2014. While the majority of respondents (8,151) were satisfied with access to their GP services, commentary included dissatisfaction at the time taken to get a routine appointment; GP opening hours; and the phone system utilised for contacting the GP service. It showed that large numbers of people were attending Out of Hours and A&E when their GP was unavailable, with 32.6% of respondents accessing Out of Hours care and 26.9% accessing A&E.

2.2 External

Thinking more broadly, publications within the last 12 months have detailed the considerations that should be given to the long-term impacts of COVID-19 and the more general concerns the public have raised surrounding their Health & Social Care. These publications helped to shape some of the questions we asked of the public, and in contextualising the responses received. We have summarised some of the main findings of these external publications below.

2.2.1 The COVID-19 Decade: Understanding the long-term societal impacts of COVID-19.[10]

[9] PCC (2014) *Access to GP Services*, PCC, Belfast.
[10] British Academy (2021), *The COVID-19 Decade: Understanding the long-term societal impacts of COVID-19*, The British Academy, London

This report was published by the British Academy in London in March 2021. As well as offering an insight into the existing impacts of the COVID-19 pandemic, it also gives predictions as to what the next 10 years will look like for Health & Social Care as a result of the pandemic.

Within this report, the authors refer to COVID-19 as *"not a socially neutral disease."* This refers to the reported statistics that Black, Asian and minority ethnic groups accounted for 34.5% of the 4,873 critically ill patients in England and Wales during the first wave; while the NI population is considerably smaller, it is likely that within Peoples' Priorities, these groups will be under-represented.

Mental health was discussed within the report, leading us to ask questions on mental health in the survey. It is suggested that the greatest mental health impact was seen in 16-24-year olds, a key consideration when evaluating the Peoples' Priorities, findings as those aged 0-24 rarely make up more than 5% of respondents.

The social distancing requirements and changes to the behaviours of Health & Social Care staff are thought to have impacted how care was being received. The British Academy described the manner of COVID-19 as having *"cut through core values and paradigms of care."*

Information access and the inequalities resulting from it are also consistent themes arising across the British Academy's report and the review of HSCB's Remote Interpretation Service, with Deaf and people with a disability stating that they felt they were being left behind and linguistic barriers playing a role.

2.2.2 Annual Complaints Reports

Each of the five Health & Social Care Trusts in Northern Ireland produce an annual Compliments and Complaints Report. The five Trusts include the Western[11], Southern[12], Northern[13], South-Eastern[14], and Belfast[15] Health & Social Care Trusts.

Across the five Trusts, for the 2019/2020 annual report, a total of 4,815 formal complaints were made, with approximately 29,469 formal compliments being made.

Across all five Trusts, the top three complaint areas were Treatment & Care (Quality), Staff Attitude/Behaviour and Communication/Information. Other areas of

[11] Western Health & Social Care Trust (2020) *Compliments & Complaints Annual Report 2019/2020*, WHSCT, Derry/Londonderry.
[12] Southern Health & Social Care Trust (2020) *Annual Quality Report 2019/2020*, SHSCT, Portadown.
[13] Northern Health & Social Care Trust (2020), *Complaints/Service User Feedback Annual Report 2019-2020*, NHSCT, Antrim.
[14] South-Eastern Health & Social Care Trust (2020), *Compliments & Complaints Annual Report 2019-2020*, SEHSCT, Newtownards
[15] Belfast Health & Social Care Trust (2020) *Complaints/Compliments Annual Report 2019-20*, BHSCT, Belfast.

complaint were Clinical Diagnosis, Professional Assessment of Need, Waiting List Delay/Cancellations (Outpatient appointments) and Waiting List Delay/Cancellations (Planned admission to hospital). The most common areas of complaint are consistent with those highlighted in the analysis of the PCC Client Support Database at **section 2.1.4** above.

2.2.3 Department of Health: Coronavirus related health inequalities[16]

This report was produced by the Department of Health to establish health inequalities resulting from the pandemic. Health inequality is already an acknowledged issue within public health and this paper outlines that infection rates in the 10% most deprived areas were higher than the rate in the 10% least deprived areas by a fifth. Levels of deprivation also appear to contribute to the likelihood of hospital admission although age had a greater impact on this throughout COVID-19.

This report outlines that there are other contributing factors to the infection and admission rates that have been seen across NI including occupation and population density. While broad demographic data will be gathered in the Peoples' Priorities survey, it will not be possible to determine if these factors have influenced the respondent's experience of Health & Social Care over the last 12 months.

Rural areas, for example Fermanagh and Omagh, had lower infection rates. It is thought that the reasons for this are related to sparse population density, in contrast to urban areas such as Belfast which had the highest infection rate. Infection rate does not equate to admission rate to hospital however, as this report outlines that the lowest standardised admission rates were seen in Mid- and East Antrim (more urbanised areas) with the highest standardised admission in Armagh City, Banbridge and Craigavon districts.

2.2.4 NI Assembly: The Impact of COVID-19 on the Health and Social Care Workforce[17]

Prior to the pandemic, the wellbeing of Health & Social Care staff had been described as being at *"an all-time low"* with mental illness, burnout, overwork and poor staff morale all presenting in high numbers. This report found that given the

[16] Department of Health. *COVID-19 in Northern Ireland - Coronavirus related health inequalities. https://www.health-ni.gov.uk/sites/default/files/publications/health/Coronavirus-related-health-inequalities-report.pdf (accessed 6 May 2021).*
[17] McMurray. S. *The Impact of COVID-19 on the Health and Social Care Workforce. http://www.niassembly.gov.uk/globalassets/documents/raise/publications/2017-2022/2020/health/3420.pdf (accessed 6 May 2021)*

perceived *"existing stigma"* that exists around mental health, many staff have not taken up support and this barrier continues to present a problem through COVID-19.

This report details how HSC workers have been faced with an increased exposure to death and suffering as well as lacking training in some instances and fearing for their own safety. Nurse stress can be attributed to unrealistic time pressures, long working hours and unachievable deadlines, whilst nurse distress is felt through the inability to provide the same standard of care given staff shortages. This theme has been reflected throughout other pieces of work. In the HSCB Remote Interpreting and Grief & Bereavement projects, service users detailed their experience of what they perceived as a detached approach by HSC staff, which they felt resulted from their experiences of the pandemic.

This report discusses the learning that can be taken from the SARS outbreak where healthcare workers made up 20% of all cases, leading to anxiety, depression, PTSD and burnout in high levels across healthcare workers following the outbreak. It suggests that without appropriate support, a *"mass exodus"* of staff could follow.

The concerns voiced by GPs in NI regarding the availability of PPE is supported by findings from the Royal College of Nursing quoted in this report, stating that nearly half of nurses operating in high-risk areas were asked to re-use items that were marked single use as per the manufacturer's guidelines.

This report raises interesting questions regarding the *"superhero label"* being applied to HSC staff and the additional pressures associated with this. It explores the mandatory redeployment of many staff to work in areas that they felt underprepared and untrained for, with this increasing work stress.

2.2.5 Queens University Belfast: COVID-19 and Mental Health[18]

This survey being conducted by researchers at Queens University Belfast aims to gather data surrounding the impact COVID-19 has had on mental health. The lead researcher stated *"the daily escalation of the seriousness of the situation will of course be anxiety-provoking for many people"*. This was also reflected through the responses received during this Peoples' Priorities work, with respondents voicing their confusion and anxiety associated with ever-changing and fluid restrictions and information.

Key stressors which have been highlighted by researchers thus far include; fears about becoming infected, having inadequate supplies and information, a sense of loneliness through isolation and feelings of boredom and frustration.

[18] Queens University Belfast. *The mental health impact of COVID-19. https://www.qub.ac.uk/coronavirus/research/related-research-activity/coronavirus-psychological-well-being-study/ (accessed 6 May 2021).*

2.2.6 Anglia Ruskin and Ulster University: Effect of COVID-19/Corona virus associated self-isolation on mental and physical health[19]

This research focuses on the impacts of COVID-19 on peoples' behaviours and the adaptation of these such as changes to diet, levels of exercise, smoking and drinking habits. The aim was to understand the health implications of the pandemic and in turn, inform governmental and healthcare bodies to allow them to be better prepared should a similar public health event happen in the future.

2.2.7 Ulster University: Correlates of symptoms of anxiety and depression and mental wellbeing associated with COVID-19: a cross-sectional study of UK-based respondents[20]

Researchers from Ulster University have undertaken a cross-sectional study of 932 UK participants to allow them to assess the impact self-isolation and social distancing on mental health and other correlating factors. They collected data on sex, age, marital status, employment status, annual income, regions, current smoking, current alcohol consumption, physical multi-morbidity, physical symptoms and the number of days spent self-isolating or social distancing.

The findings suggest that sex, age, annual income, current smoking and physical multi-morbidity were associated with poor mental health. This supports findings displayed in COVID-19: The Long Decade (**Section 2.2.1**) which found that females, younger generations, and those of lower socioeconomic status were at greater risk of poor mental health as a result of the pandemic.

2.2.8 Ulster University: Demographic and health factors associated with pandemic anxiety during the COVID-19 outbreak[21]

Ulster University has produced the Pandemic Anxiety Scale through a sample of 4,793 parents and 698 adolescents. This scale assists to identify specific elements of the pandemic which are causing anxiety. Two main areas emerged; disease

[19] Anglia Ruskin University. *Public asked to participate in self-isolation research. https://aru.ac.uk/news/public-asked-to-participate-in-self-isolation-research (accessed 6 May 2021).*
[20] Smith L, Jacob L, Yakkundi A, McDermott D, Armstrong N, Barnett Y et al.. Correlates of symptoms of anxiety and depression and mental wellbeing associated with COVID-19: a cross-sectional study of UK-based respondents. *Psychiatry research* 2020; 291(): . https://pure.ulster.ac.uk/en/publications/correlates-of-symptoms-of-anxiety-and-depression-and-mental-wellb (accessed 6 May 2021)
[21] McElroy E, Patalay P, Moltrecht B, Shevlin M, Shum A, Creswell C et al.. Demographic and health factors associated with pandemic anxiety in the context of COVID-19. *British Journal of Health Psychology* 2020; 25(4): . https://pure.ulster.ac.uk/en/publications/demographic-and-health-factors-associated-with-pandemic-anxiety-i (accessed 6 May 2021).

anxiety i.e. fears of catching or transmitting COVID-19, and consequence anxiety i.e. the impacts on economic prospects. Anxiety in these areas was evidenced across both the parental group and the adolescent group. The research noted a correlation with sex and age as being linked to pandemic anxiety. They also report that physical ill-health and income are associated with this heightened anxiety.

3 Methodology

3.1 Data collection

Our approach to this work was to use both quantitative and qualitative methods to gather peoples' views and opinions on their experience of HSC services and information provision during the COVID-19 pandemic in Northern Ireland. This report reflects what respondents told us.

3.1.1 Survey

The main method of capturing peoples' views was through an online survey. With the ongoing COVID-19 pandemic, we decided not to carry out in-person/face to face engagement however we did facilitate a number of virtual engagement events.

Feedback on the survey's design and questions was gathered from a focus group of PCC members in December 2020. From the feedback, we implemented a number of changes before a final survey was launched (see **appendix 1)**. Respondents could fill out the survey by themselves or on behalf of someone else. All survey responses were merged and analysed together. The survey ran from 21st December and closed 31st March.

In addition to the standard version of the survey, an easy read version was made, (see **appendix 2)**. We were aware that completing the survey online would not be an accessible option for all members of the public. To make the survey as accessible as possible, participants were able to request a paper copy of the survey that they could return via post, or they could complete the survey over the telephone. Participants were asked the same set of questions as the online survey, with their responses recorded and inputted by a member of PCC staff.

The survey was promoted through our membership scheme, social media channels and other networks.

3.1.2 Focus groups

A number of focus groups facilitated by PCC staff between January and March 2021 took place. These were held through video conferencing services. Invitations to join the focus groups were sent out through voluntary organisations and community groups. There was also an option to attend further discussions when completing the online survey.

In the focus groups, participants had the opportunity to discuss their experiences of HSC during COVID-19 in detail. The questions asked were adapted from the survey questions, and had a similar focus. In focus group discussions PCC staff were able to use additional prompting questions as and when appropriate to clarify and expand on information shared.

3.2 Data Analysis

Once the online survey closed, quantitative analysis of the categorical response data was conducted, with qualitative analysis of the free text responses. During the survey period, the PCC Council explored and discussed emerging themes and messages, which assisted the in the development of appropriate themes. These themes were developed into a coding frame for each free text question in MS Excel, which allowed each response to be assigned one or more codes or themes during the full analysis. Codes were then counted and analysed to identify common themes, views and experiences within responses. Where responses did not fit the identified themes, the Research team agreed to add themes (or modify) where necessary. A quantitative data analysis was conducted to see the frequency of results and the demographics of the respondents.

Next, the focus group data was analysed, again with key themes being identified and categorised, mirroring the thematic analysis from the survey.

Together the survey and focus group data helped us to shape the prevailing themes and draw up the top HSC priorities of respondents. This led to a third stage of data collection, whereby additional material was gathered from the client database used by PCC to record advocacy casework, and external literature in order to contextualise some of the emerging themes.

3.3 Limitations

There are limitations to the scope of this Peoples' Priorities report which must be acknowledged going forward and in the context of which this report should be read.

Representation and demographic information collected

As evidenced in the literature review, the survey and focus groups conducted by the PCC did not gather information on peoples' level of education or their socio-economic status, which have been highlighted as areas that impact perceptions as well as accessibility of care.

Methods for engagement

We recognise that having the focus groups online may have discouraged some potential participants who were not comfortable with technology or speaking online.

Furthermore, we may have missed people who do not use social media or were not part of one of the groups we distributed the survey to. Vulnerable and minority groups may have also been missed due to the lack of face to face engagement.

Responses

This report reflects what people told us. We recognise that some peoples' experience will not be reflected in this report as the findings presented are only a snapshot and cannot be considered as representative of the whole of NI's population and their experiences. While this work has been somewhat successful in reaching rural communities, it has not been as successful in reaching Black and Minority Ethnic groups (BAME). Very few people from the BAME community participated in either the survey or focus groups.

Survey at a point in time

It should also be noted that this report captures peoples' views and experiences at a specific time in the pandemic, between December 2020- March 2021. During this period, rates of COVID-19 cases had risen again and another lockdown had occurred which may have impacted on survey findings.

4 Findings

4.1 Demographics

A total of 1,056 people contributed their views and opinions on HSC during the COVID-19 pandemic in Northern Ireland.

4.1.1 Profile of questionnaire respondents.

In total, 1,008 members of the public completed the survey. A breakdown of the demographics of respondents can be found in **Table 1** below.

Out of the 1,008 respondents, 948 (94%) completed the survey for themselves, and 60 (6%) completed the survey on behalf of someone else.

For those respondents completing the survey on behalf of someone else, they were asked what their relationship to the person was. Of the 60;

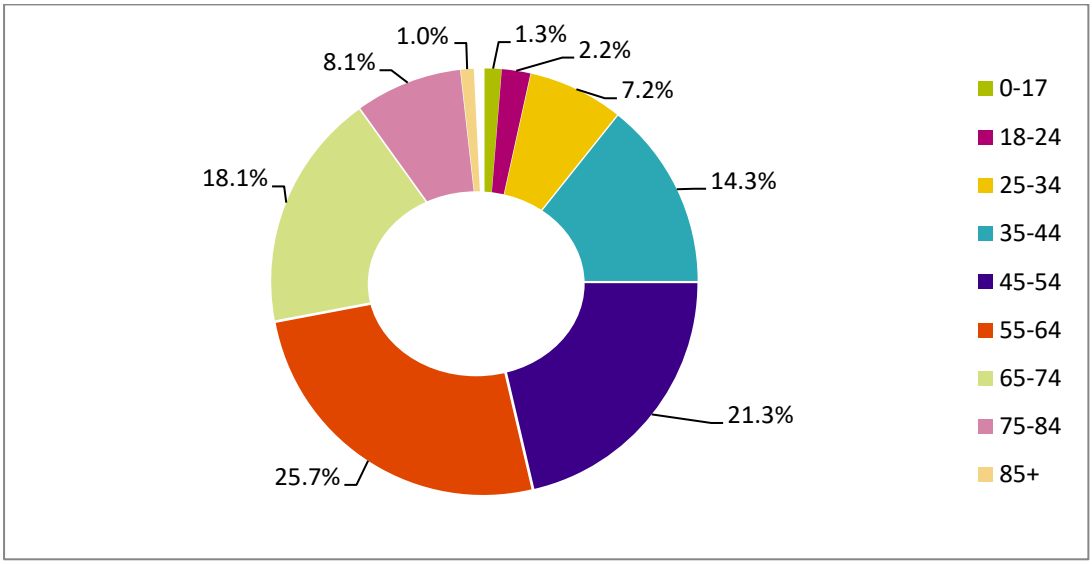
- 18 respondents completed the survey on behalf of their child
- 17 respondents completed the survey on behalf of their parent
- 11 respondents completed the survey on behalf of their partner / spouse
- 6 respondents completed the survey on behalf of their friend
- 8 respondents chose “Other”. Other relationships included siblings, in-laws and service users.

Table 1: Breakdown of respondents by gender identity

Gender	Number	% of total respondents
Male	272	26.9%
Female	718	71.8%
Other	2	0.2%
Prefer not to say	16	1.6%
Total	**1,008**	**1,008**

Over 70% of respondents were female, similar to surveys we’ve hosted in the past, such as the Peoples’ Priorities survey in 2016. This also reflects the PCC’s membership scheme in which, 27% identify as male and 73% identify as female.

Figure 1: Graph showing age ranges of respondents



In comparison, within the PCC membership 8% of members are in the 18-24 age range, 13% are in the 25-34 age range, 12% are in the 35-44 age range, 16% are in the 45-54 age range 18% are in the 55-64 age range and 33% are in the 65+ age range.

Table 2: Ethnic backgrounds of respondents

Ethnic background	Number of respondents	Percentage
White	975	96.7%
Chinese	4	0.4%
Prefer not to say	4	0.4%
Other	2	0.2%
Mixed ethnic	2	0.2%
Indian	1	0.1%
Irish Traveller	1	0.1%
Blank	19	1.9%
Grand Total	**1008**	100.0%

Most respondents were aged 45 – 64 years (**Figure 1**) and came from a White background (**Table 2**).

Of the 1,008 respondents;

- 689 (68.4%) said they did not consider themselves to have a disability
- 314 (31.2%) said they did consider themselves to have a disability
- 5 (0.5%) declined to answer

The demographic variables seen across the survey respondents follow a similar trajectory outlined in other pieces of research, such as the report produced by the British Academy which acknowledges that BME groups, those with disabilities and younger people are under-represented groups.[10]

Table 3: Breakdown of respondents by HSC Trust area

HSCT Area	Number	% of total respondents
BHSCT	233	24.1%
WHSCT	226	23.4%
SEHSCT	189	19.6%
SHSCT	159	16.5%
NHSCT	158	16.4%
Don't Know	22	2.3%
Total	**965**	**100.0%**

There is a contrast between the number of calls received to the PCC Client Support Services (**Table 4**) regarding services in a particular HSCT area, and the number of respondents to the Peoples' Priorities survey (**Table 3**) from that area. The WHSCT made up only 8.3% of support calls to the PCC in 2020-2021 but contributed to 23.4% of survey respondents. Similarly, clients from the SEHSCT made up 10.2% of calls to the client support service in the same timeframe but survey respondents from this same trust area presented in almost double this number. In the SHSCT, 16.5% of survey respondents came from this area compared to 9.3% of callers in year. In comparison to the PCC membership scheme, 16% reside in the BHSCT, 24% reside in the NHSCT, 14% reside in the SEHSCT, 19% reside in the SHCST and 27% reside in the WHSCT.

Table 4: Breakdown of Client Support clients by HSC Trust area (FY 2020 / 2021)

HSCT Area	Total	%
BHSCT	168	24.9%
NHSCT	117	17.3%
SEHSCT	69	10.2%
SHSCT	63	9.3%
WHSCT	56	8.3%
NIAS	4	0.6%

4.1.2 Focus group participants

A number of focus groups facilitated by PCC staff were held with community and voluntary organisations. They helped us to talk to people who wanted to provide their views and needed assistance to do so or were part of their network. The focus groups offered the opportunity for further discussion on the survey also.

A total of 47 people took part in a focus group. **Table 5** provides details of the focus groups.

Table 5: Focus Groups

Type of Group	Date Held	Number of Participants
Survey Focus Group	18th January	3
Dementia NI	3rd February	10
British Sign Language	4th February	4
Cedar Foundation	9th February	2
Irish Sign Language	16th February	5
Action Mental Health	17th February	4
Survey Focus Group	18th February	4
Headway	19th February	7
Action Mental Health	2nd March	2
Survey Focus Group	10th March	3
Survey Focus Group	11th March	3

In the focus groups, participants had the opportunity to discuss their recent experience of HSC in detail. They shared their personal experiences of using HSC services during the pandemic, and spoke about information provision. Participants spoke to us about what worked well and what didn't. Where appropriate, PCC staff would ask further questions on points made to allow the group to explore a topic further.

4.2 Health and social care provision

Of those who said they had accessed HSC services since March 2020 (n=765), respondents were asked which service they had used most frequently since March 2020. The top five services that respondents came in contact with can be seen in **Table 6.**

Table 6: Top 5 services respondents came in contact with most frequently since March 2020

Speciality	Number of people
GP and GP out of hours	334
Other	115
Accident & Emergency	54
Pharmacy	45
Dental	28

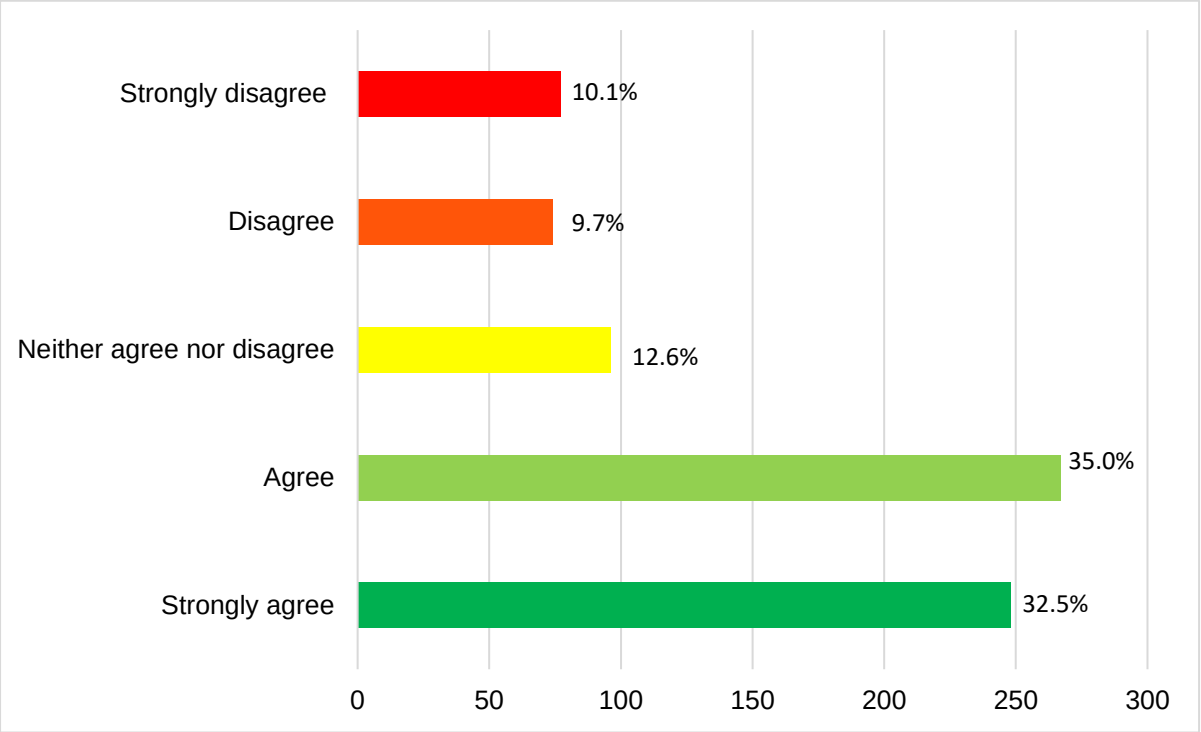
The top four services from our client database in 2020-2021 can be seen in **Table 7**.

Table 7: Top 4 services from Client Support database (FY2020-2021)

Main Service	Total	%
GP	92	13.6%
Mental Health	56	8.3%
Residential & Nursing Homes	46	6.8%
Elderly Care	46	6.8%

In response to the question about whether respondents hadn't accessed HSC services due to confirmed or suspected COVID-19: 94.3% (n=718/761) said no this was not the reason, whilst 5.4% (n=41/761) said yes, a confirmed or suspected case was the reason they did not access HSC services. A further 0.3% (n=2/761) said they didn't know whether this was the reason.

Figure 2: Graph showing to what extent respondents agreed that they were satisfied with the service provided



When asked to what extent they were satisfied with the service provided, the majority (67.6%) (n=515/762), said that they agreed or strongly agreed that they were satisfied with the service provided (**Figure 2**). However, some respondents (19.8%) (n=151/762) said that they disagreed or strongly disagreed with the statement, and 12.6% (n=96/762) said that they neither agreed nor disagreed with the statement. Some comments from respondents are included below:

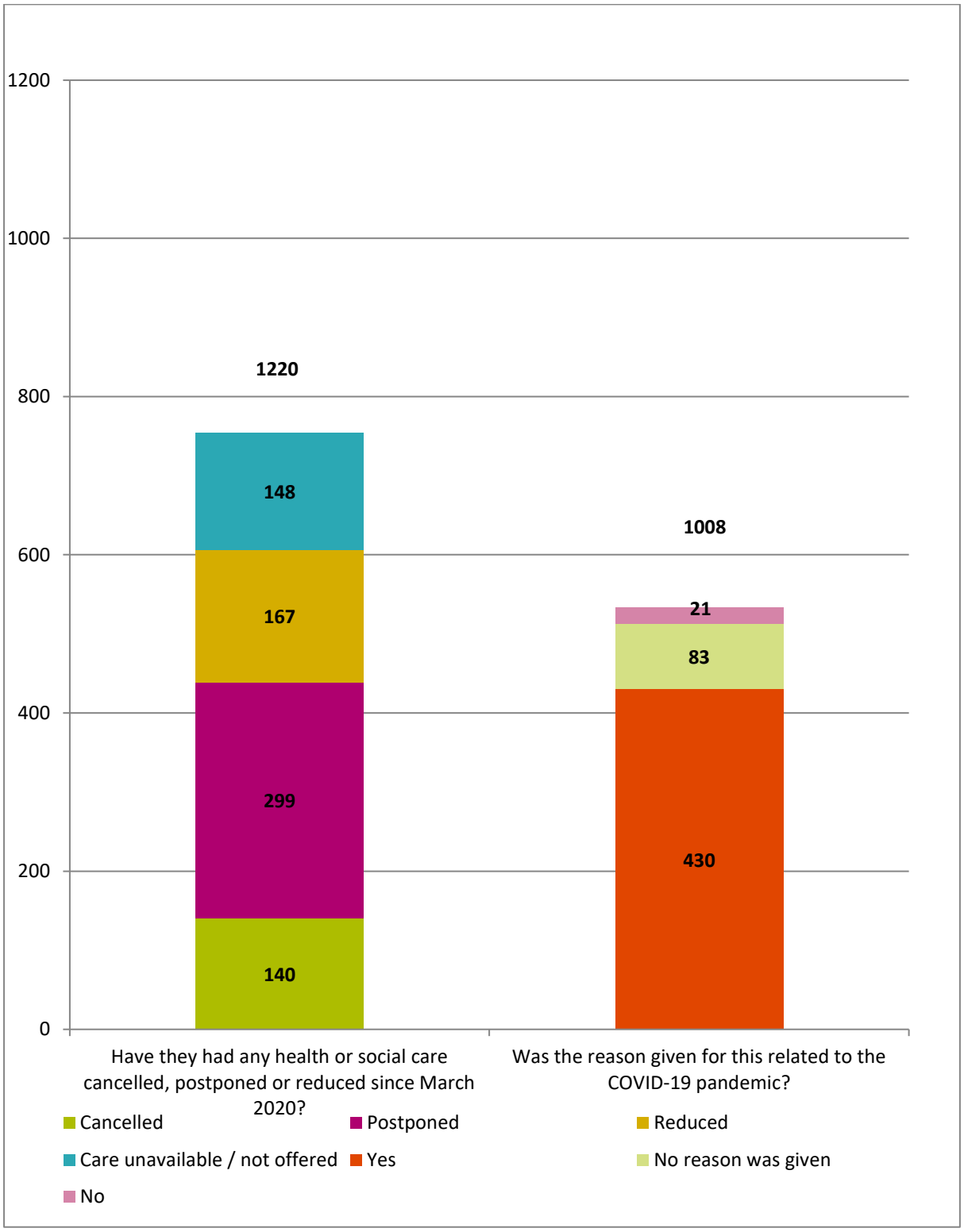
"Adjustments were made and I was able to access some services at my GP and in a safe way get some screening done also" **Female, Survey Respondent**	*"Consultants and nurses still tried to help me even though face to face appointments were cancelled"* **Male, Survey Respondent**
"GP offered a phone back service which I used to speak to them and then received the medication I required." **Female, Survey Respondent**	*"I attended my GP surgery for a flu vaccination and also a COVID-19 vaccination. Given the current circumstances the procedures were well organised.* **Female, Survey Respondent**

"Very happy with consultants care and time spent assessing my case" **Female, Survey Respondent**	*"As a day patient I was treated with the upmost respect and compassion and throughout my visit was very aware of how careful all staff were regarding PPE and distancing."* **Male, Survey Respondent**
"Getting a GP appointment was problematic and a referral to consultant then meant at least [a] *12 month wait"* **Survey Respondent**	*"It is very difficult to see and speak to a doctor, there is a time slot when patients can ring to book a telephone appointment but all the appointments are usually gone in about 20 minutes so you have to try next day."* **Female, Survey Respondent**
"Rushed telephone appointments with lack of practical support or understanding." **Female, Survey Respondent**	

Figure 3: Word cloud showing free text codes for responses to question 38, ‘to what extent do you agree that you were satisfied with the service provided?’

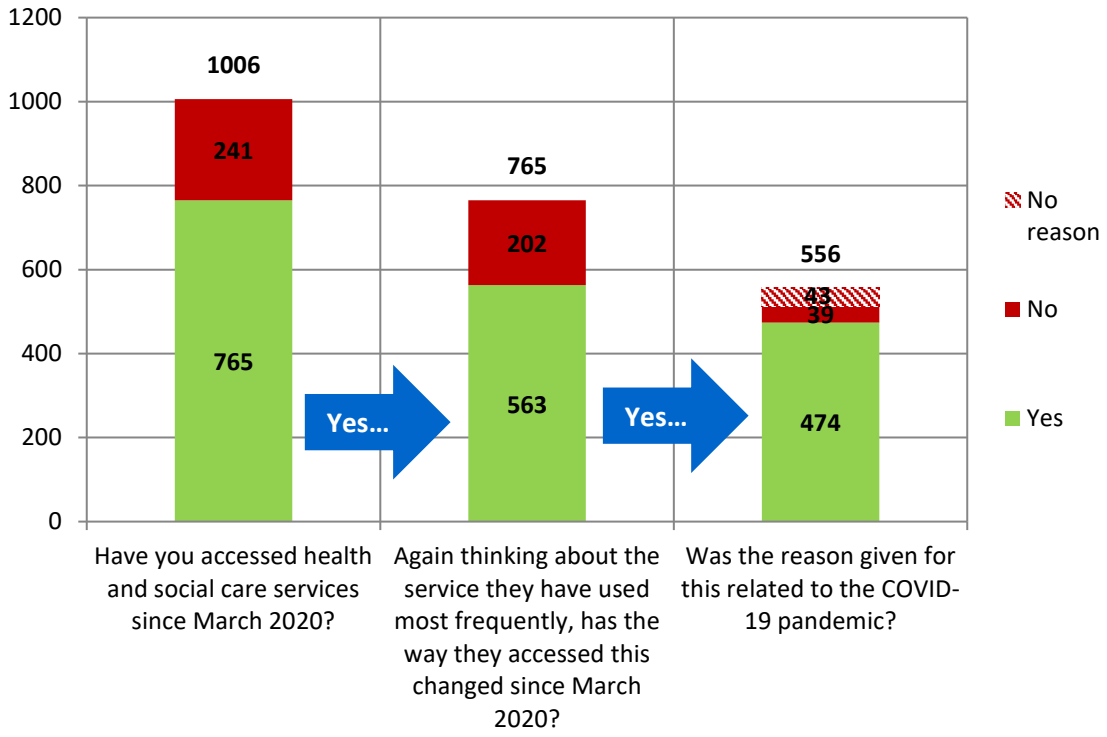
When asked if their routine HSC had been cancelled, postponed or impacted, and whether COVID-19 was to blame, 534 (53.0%) respondents believed their care had been interrupted. Of these, 80.5% knew that it was as a result of COVID-19. Less than 4% knew it was due to other factors and 15.5% had no reason given.

Figure 4: Graph showing the impact of COVID-19 on routine care



4.3 Changes to accessing health and social care services

Figure 5: Graph showing an overview of how services have changed since March 2020



When asked if HSC services had changed since March 2020, 73.6% (n=563/765) said they had changed, while 26.4% (n=202/765) said they had not changed (**Figure 5**). When asked how services had changed, the majority said their appointment was now conducted by telephone or video call. Opinions were mixed on how satisfied they were on these changes. Almost a fifth (19.8%, n=97/491) missed having face to face contact with a medical professional however some said they felt safer not having to go to a HSC setting. The comments below demonstrated some of these changes and how respondents experienced them:

"I would always go to my GP for my own health reasons but now you can see your GP you have to talk to him over the phone. Some GPs don't want to see any patients at the surgery." **Female, Focus Group Respondent**	*"Telephone calls, there's no real problems with it,* [I'm] *not really happy with it but I've been putting up with it due to COVID-19."* **Male, Focus Group Respondent**

"I had a virtual telephone assessment with my physiotherapist" **Male, Focus Group Respondent**	*"There's only phone services for the GP and NHS. Doctors don't want to see you, just over the phone."* **Female, Focus Group Respondent**
"Even though I've not many hands-on encounters in hospital I had a very complete virtual programme with diet, and physiotherapy and meds, on a weekly basis. So, I had honestly a positive experience of services" **Male, Focus Group Respondent**	*"Appointments are over the phone and I was able to send pictures via text message."* **Female, Survey Respondent**
"Appointments have been by telephone and I find these to be more beneficial" **Female, Survey Respondent**	*"GP surgery is no longer walk in. Most queries are telephone triage. Then an appointment is made."* **Female, Survey Respondent**
"It has been conducted by telephone and the appropriate medical care was given to me. I felt quite satisfied with this level of care as it offered me safety during lockdown." **Female, Survey Respondent**	*"GP triage by phone. It's harder to get through on the phone and with no option to call in, you feel isolated from GP services."* **Female, Survey Respondent**

When asked if the reason given for changes to the delivery of services was related to the COVID-19 pandemic, the majority of respondents, 85.3% (n=474/556) said yes, 7.7% (n=43/556) said no, and 7.0% (n=39/556), said that there was no reason given.

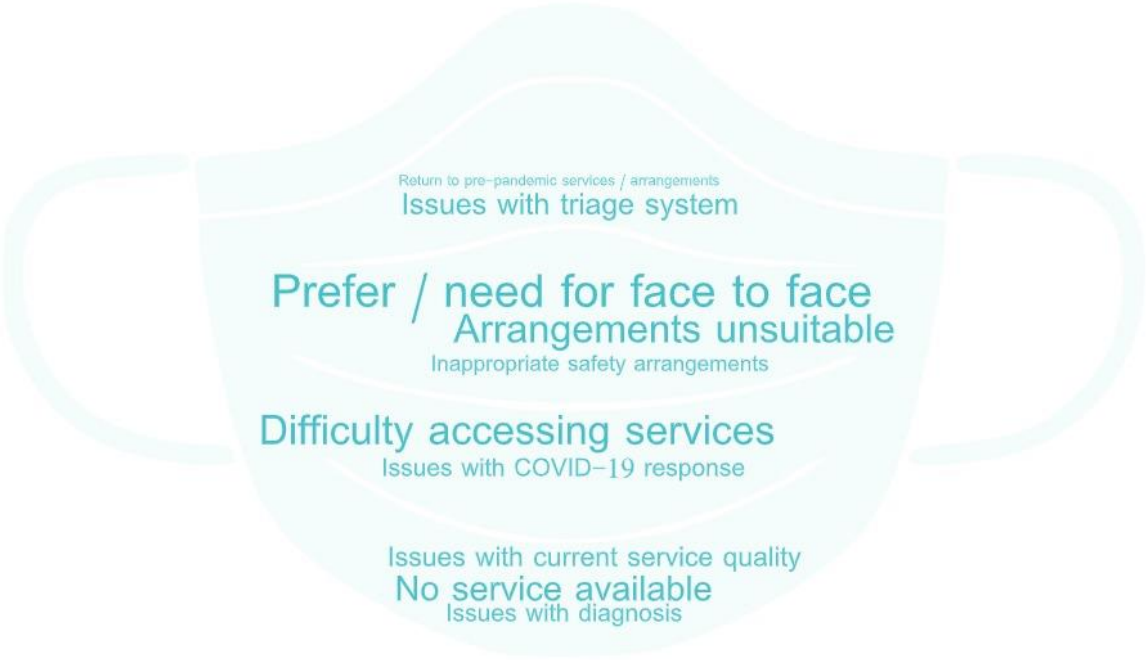
Respondents were asked if they would be happy to continue using the service in this way. There was a split across responses to this question; 43.1% (n=241/559) said yes, they would be happy to continue using services this way, and 41.7% (n=233/559) said no they would not be happy to continue using services this way. In addition, 15.2% said they 'don't know' (n=85/559) and were unsure about services continuing to operate in this different way.

Reasons given for respondents not wanting services to continue as they are included preference for face to face services, difficulty accessing services as they are, and unsuitable arrangements.

Some other people discussed the benefits of having a telephone system and a hybrid approach, recognising that it can't be one or the other, it needs to be both:

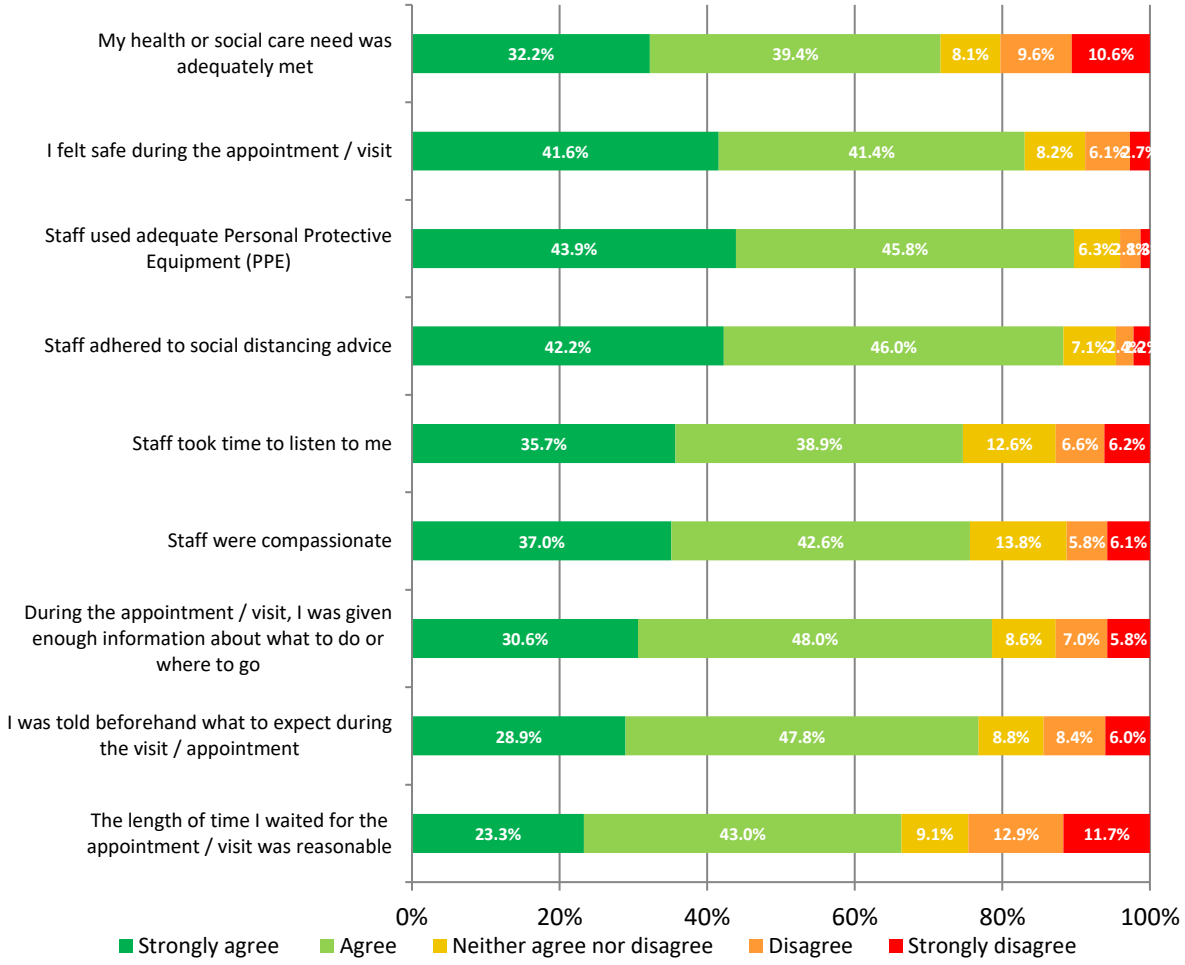
- "*I feel for some issues its fine to have a telephone consultation but my mother had her heart review via the telephone which makes me feel incredibly uncomfortable."*
- "*I don't mind using the telephone appointments in future, and I think it is a good way to deal with some issues but I think a better triage system needs to be in place."*
- *"Depending on the medical issue a telephone appointment may suffice."*

Figure 6: Word cloud showing free-text codes for responses to question 41, 'would respondents be happy for services to continue in this way?'



In the survey, respondents were asked to what extent they agreed with a number of statements about their most recent contact with HSC services. From these statements we could gauge the areas of most and least concern. Overall, as seen in **Figure 7,** responses to this question indicate that respondents felt that the risks of COVID-19 were being adequately managed during respondents' contact(s) with HSC services. However, there were lower levels of satisfaction with how long people had to wait and with the actual outcome of the contact.

Figure 7: Graph showing the extent to which people felt they were adequately informed around certain areas and issues related to COVID-19



The majority, 89.7% (n=574/640), of respondents said that they agreed or strongly agreed with the statement *'staff used adequate PPE'*. Similarly, 88.3% (n=558/632) of respondents said they agreed or strongly agreed that staff adhered to social distancing advice. Almost a quarter (n=168/683) of people said that they disagreed or strongly disagreed that the length of time for an appointment/visit was reasonable. Whilst 71.6% strongly agreed & agreed with the statement '*my health or social care need was adequately met,*' a fifth (20.2%) (n=147/726) of people said that they disagreed or strongly disagreed with this statement.

5 Analysis

There were five key themes arising out of the Peoples' Priorities survey, each with sub themes identified after careful cross coding and textual analysis. The findings are combined here and discussed by theme;

5.1 Quality of Care and Access to Services

It is important to recognise and understand the pressures facing healthcare professionals before discussing the positive and negative experiences of patients with frontline staff care throughout COVID-19.

Healthcare systems across the UK were under pre-existing pressures prior to the COVID-19 crisis; acute staff shortages, lengthy waiting lists, increasing patient demand and significant budget deficits were some of the challenges the health service was facing[22]. Undoubtedly, these pressures have taken their toll on the professionals operating our Health & Social Care systems, on their physical and emotional wellbeing and mental health. These pressures have been acknowledged by the respondents of the Peoples' Priorities survey in some instances also; *"staff have been doing their best under an extreme set of circumstances and that should not be discounted or taken for granted."*

Concerns surrounding the psychological wellbeing of staff have been intensified with the emergence of COVID-19; the intense demands placed on doctors, nurses, social care workers and other healthcare professionals while working through this global crisis have been considerable. This, alongside the long working hours and exposure to large scale deaths across hospitals, has led to burnout of staff. Exhaustion, cynicism, and decreased effectiveness at work as well as impaired decision making have been reported as some of the resulting difficulties faced by healthcare staff[23].

The British Medical Association has also reported that 80% of doctors were at either high or very high risk of burnout, with junior doctors found to be most at risk.[24] Within nursing, 42% of UK nurses reported burnout; a considerably higher number than the

[22] Albott CS MD, Wozniak JR PhD, McGlinch BP MD, Wall MH MD, Gold BS MD & Vinogradov S MD.. Battle Buddies: Rapid Deployment of a Psychological Resilience Intervention for Health Care Workers During the Coronavirus Disease 2019 Pandemic. *Anesth Analg* 2020; 131(): . https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7199769/#R13 (accessed 6 May 2021).
[23] Connolly ML. *Coronavirus: GPs may 'withdraw services over lack of PPE'. https://www.bbc.co.uk/news/uk-northern-ireland-52265857 (accessed 6 May 2021).*
[24] British Medical Academy. *Under fire on the front line – doctors share their experiences of work during the COVID-19 crisis. https://www.bma.org.uk/news-and-opinion/under-fire-on-the-front-line-doctors-share-their-experiences-of-work-during-the-COVID-19-crisis (accessed 6 May 2021).*

European average of 28%[25]. The Scottish trade union GMB also report that 4 in 5 care staff say their mental health has been damaged by their work.[26]

In Italian hospitals, during COVID-19, the younger healthcare staff were more at risk of PTSD, severe depression, anxiety, insomnia and stress when compared with their older colleagues.[27]

For GPs in Northern Ireland and those working in mental health settings, the struggle in accessing adequate PPE was found to be both stressful and frustrating. These concerns had led to a number of doctors considering suspension of services, with feelings of anxiety and fear prevalent.[23]A briefing produced by the NI Assembly also highlights the anxiety and stress physicians are faced with when being forced to make decisions that require choosing between their patients care and their own protection.[17]

It is within this context that the short, medium- and long-term implications of the impact of COVID-19 on the medical workforce in NI and on services must be considered. The COVID-19 pandemic has presented an unprecedented challenge for healthcare workers and supporting their mental health has become a critical part of the overall public health response.

The BMA has stated that sufficient time away from work must be afforded to staff to allow them to process their experiences and to avoid chronic burnout.[25] With this comes the potential that GP services and other primary care facilities will continue on this trajectory of disrupted access into the near future. Self-care and messages spread among the public to this effect may prove to be vitally important to aid the medical profession in their recovery from the impact of COVID-19.

The purpose of the Peoples' Priorities survey was to understand peoples' experiences, positive and negative, of using HSC services during the COVID-19. We did not set out to gather specific feedback on GPs and Primary Care. However, our findings highlight some of the concerns raised by the public in relation to GPs and primary care. It should be noted the contradictory impact on ways of working that COVID-19 has brought with it for those in caring professions; the British Academy suggested the pandemic had *"cut through the core paradigms of care"*[10] i.e. the requirement to socially distance, wear PPE, and the impact of this on provider and

[25] Health Education England. *Growing Nursing Numbers Literature review on nurses leaving the NHS. https://www.hee.nhs.uk/sites/default/files/documents/Nurses%20leaving%20practice%20-%20Literature%20Review.pdf (accessed 6 May 2021).*
[26] Smith P.. *Mental health 'damaged' in majority of Scottish coronavirus carers. https://www.itv.com/news/2020-04-17/mental-health-of-80-of-carers-treating-COVID-19-patients-in-scotland-has-been-damaged-survey-seen-by-itv-news-reveals (accessed 6 May 2021).*
[27] Rossi R MD, Socci V PhD, Pacitti F MD, Di Lorenzo G MD, Di Marco A PhD, Siracusano A MD et al.. Mental Health Outcomes Among Frontline and Second-Line Health Care Workers During the Coronavirus Disease 2019 (COVID-19) Pandemic in Italy. *JAMA Netw Open* 2020; 3(5): . https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2766378 (accessed 6 May 2021).

service user relationships will have affected peoples' experiences of care, and the experiences of the care-giver, on a deeper level.

In addition to concerns raised through our report, the PCC Client Support service received more complaints focusing on GP services in the last 12 months; 13.6% of contacts from 2020-2021 related to GPs, with 40.2% of these relating to the submission of a formal complaint.[8]

The top five complaint areas seen by the Client Support team in relation to this service related to medication (23.9%); staff attitude (20.7%); communication (18.5%); quality of treatment and care (13.0%) and diagnosis (7.6%). The statistics presented would suggest that the provision of GP services, the manner in which they are offered, and the interactions service users have with their respective GP surgeries have been a source of concern over the past 12 months. While the results from the Peoples' Priorities paint a positive picture in some ways, the individual commentary, alongside other pieces of data, highlight peoples' concerns in relation to aspects of GP service provision.

Despite the undoubted harmful impact the pandemic has had on staff, many of the Peoples' Priorities respondents shared positive comments and gratitude for the staff, such as the following; *"My experience of health and social care medical and nursing staff during the COVID-19 pandemic is one of admiration… they have shown how well they can work under pressure."* Around 32.7% of responses to question 38a gave praise and expressed understanding for the circumstances that HSC staff were faced with.

There was also some negative feedback in relation to experiences with HSC staff, particularly in terms of attitude and communication for example; *"The rude receptionist makes the whole process a lot more stressful"* and *"My GP has been awful, disinterested, and plain rude."*

Quality of care, waiting times, interruption to services, information sharing, and accessing services all emerged as key themes through the data analysis. These themes mirror key complaint areas faced by Client Support services daily, as well as themes evident through external literature such as the Health & Social Care Trusts' annual complaints reports.[11][12][13][14][15]

Within the Peoples' Priorities survey, 28.6% of respondents did not feel that staff had shown compassion towards them, and 31% felt that staff had not taken time to listen to them and their concerns. This supports the figures seen from the Client Support caseload as mentioned previously (**Table 8**):

Table 8: Number of PCC Client Support cases regarding staff attitude by type of case

Type	Number of cases	%
Advocacy/Formal complaint	49	49%
Advocacy/Issue/concern	21	21%
Advocacy/Information only	16	16%
Advice	14	14%
Grand Total	**100**	**100**

Whilst some respondents did not have difficulties accessing GP services, just under a quarter (24%, n=80/334) reported difficulties. They said they found it difficult to access services, including having to wait a long time to see a GP. Participants in the 2021 focus groups highlighted a range of issues. *"You just can't get an appointment…"* and *"It's so frustrating… the system is stressful."* These difficulties mirror those that were highlighted in both the Access to GPs report in 2014[9] and the previous Peoples' Priorities in 2016[28]

A number of concerns reported through the Peoples' Priorities of 2021 reiterate those seen in 2016 also. Many service users highlighted the move to phone triaging and 69% stated that their service had moved to phone appointments and consultations or triage, and a further 7% described limited or indeed no access to services. When questionnaire respondents in 2016 were asked to identify one thing they would change about accessing their GP practice, three common issues were identified, and based on the figures seen it is clear these issues still exist:

1. Access to appointments such as working through the booking system and the time it took to get a routine appointment (27.6%)
2. Opening hours (17.5%)
3. The phone system for contacting their GP service (14.0%)[28]

It is important to note that any changes to or extension of the GP practice openings hours is a contractual issue, between the SPPG (Strategic Planning and Performance Group) and GP practices, and would require changes to the funding of GP practices. The Strategic Planning and Performance Group (formerly the Health and Social Care Board) plans and oversees the delivery of HSC services for the population of Northern Ireland. It sits within the Department of Health.

During the pandemic, GPs employed telephone systems to try and manage appointments and care. This approach was met by both positive and negative feedback with some respondents outlining the challenges with this system: *"[The]*

[28] Patient and Client Council (2016) *The Peoples' Priorities*, PCC, Belfast

surgery operates a call quota system. Once the daily limit is reached they won't deal with any more calls so can lead to long delays in access."

Access to appointments and the publics' experience of being able to access timely appointments, differed across the feedback we received. Some found they were able to see their GP for regular services such as blood tests, while others had not had their had their usual tests completed in over a year. Some people reported feeling frustrated by this difference in service provision; *"For those with good GPs it [the system] works… for those who don't you're left alone."* Within the PCC Client Support service, 7.5% (n=7/92) of GP related complaints were to do with Waiting Times, Delays and Cancellations.

A number of respondents emphasised how important GPs are and how they are the gateway to other services. GP referrals declined by 58% between March-May 2020.[10] It should be noted that this decline correlated with a reduction in patients accessing NHS services due to strict lockdown measures at the height of the COVID-19 pandemic. In relation to the overarching Health & Social Care systems being heavily reliant on GP referral systems and care pathways, one focus group attendee outlined concerns that *"without them working to their ability it won't work as a whole"*.

Under the category of Primary Care also comes dentistry. Of those who said that dental care was their main contact with HSC services (n=29/1,006) respondents said they had issues with long wait times to be seen often leaving them in pain. Seventy six percent (n=22/29) of these respondents had their care cancelled, postponed, delayed or not offered, and over three quarters of those who had their care changed in this way stated that the excuse given was related to COVID-19.

The majority (62.1% (n=18/29) agreed or strongly agreed that they were satisfied with the service used, with those stating otherwise citing issues such as long waits for treatment and difficulties with accessing services. **Table 9** below showcases the complaint areas for dental care.

Table 9: Complaints areas of Dentist related PCC Client Support cases: Complaints areas of Dentist related PCC Client Support cases

Complaint Area	Total	%
Treatment and care – Quality	4	100%
Staff attitude	1	25%
Communication	1	25%

It is clear from the context offered through the Peoples' Priorities survey, the Client Support caseload, external literature, and other pieces of PCC work that the concerns surrounding primary care are not isolated to the COVID-19 pandemic; rather they have been intensified as a result. This is also detailed by the British

Academy in their publication on the long-term impacts of the pandemic, suggesting that 1 in 10 people report being unable to speak to their GP about their symptoms.[10]

The impact of COVID-19 on the provision of care cannot be discounted when reviewing the level of complaints related to A&E services. The need for healthcare professionals to protect themselves and colleagues, while also trying to treat their patient, has undoubtedly changed the dynamic of care that we are used to; something again highlighted by the British Academy.[10] The British Academy report also stated that within the UK there was actually a drop of 56.6% in the number of people attending A&E in April 2020; although there were concerns that this was down to avoidance due to fear of catching the virus.

Whilst some respondents reported positive experiences of A&E services, describing A&E staff as kind and pleasant, some had negative experiences of delays, long waits, poor communication and poor information. The link between the care received in A&E and COVID-19 has been acknowledged by many with respondents appreciating the level of care *"given the circumstances."* Again, the impact of COVID-19 on interactions, availability of services and waiting times is likely to have played an important role in the responses obtained.

Positive work has already commenced through the No More Silos Network to ensure hospital services have primary care facing pathways to make sure patients who need care escalated and clinical risk shared will be able to access hospital services without needing to attend busy emergency departments.

Mental Health services remain an issue for respondents in 2021. In the survey and focus groups 24 respondents said mental health services had been their main contact with HSC during the pandemic; all stated these services had changed since March 2020. Through the 2016 Peoples' Priorities report 'Improve mental health care' was the 5th top priority.[28] One way services had changed was a move to more telephone appointments, consistent with other literature in the UK.[10]

> *"Before COVID-19, I had regular and consistent support for my mental health. Then COVID-19 hit and at the start all my support was brought to a complete stop. It slowly built up, but it is still not where it was pre-COVID-19. Because of lack of support and the additional stresses due to COVID-19, my mental health took a major dip and I had to be admitted."*
>
> **Female, survey respondent**

Some respondents felt that telephone services are not as effective as face to face contacts, with some worries around the level of care available through telephone consultations. Some felt that not being able to see the patient was harmful; *"Mental health requires a lot of face to face time to enable the service to work. This simply isn't there over the phone."* The sentiment expressed here was also found within work on Grief & Bereavement through COVID-19 that the PCC completed in partnership with Marie Curie.[5] Participants in focus groups for this

project shared that accessing mental health and bereavement support via telephone or video call posed a significant barrier and for numerous people was a primary reason they did not avail of these services.[5]

> *"there's no alternative given like talking therapies.* [The] *GP basically says to take your medication and see him in six weeks"*
>
> **Male, focus group**

Respondents expressed concern at the lack of alternative services, with the focus instead on medications. *"*[The] *doctors think if you just take your medication you'll be OK, but it's more than just that"* was an opinion shared by one focus group attendee for Peoples' Priorities.

These experiences show some of the difficulties faced by those with mental health issues and how they may need alternatives and appropriate care, which is not sustainable under the current processes i.e. telephone appointments. Respondents highlighted specifically that telephone appointments were not working for them and stated the need to return to face to face appointments as they consider them to be *"more meaningful" – "Patients should have the option of seeing their mental health networker or doctor as a face to face appointment".*

Whilst the inaccessibility of phone appointments for mental health patients has been acknowledged throughout Peoples' Priorities feedback and the external literature, some felt they did cope with the changes that resulted from COVID-19. This was primarily down to the efforts of HSC staff to make services adaptable and workable for the individual, like the following survey response highlights: *"My clinical psychologist switched to remote practice for outpatients due to COVID-19 and has been very flexible and supportive…after discussions with me and another member of my medical team, we agreed I would be seen weekly instead of fortnightly."*

This flexibility demonstrates the impact staff attitudes can have on patient care throughout the pandemic. The right support in the right way is important and can result in patients feeling better able to manage their health.

A reliance on organisations external to the health and social care system emerged as a theme, with the Samaritans being described by one focus group attendee as "*the be all and end all"*. This is discussed in the next section of this report.

5.2 Alternative Provision

5.2.1 VCSE

Many respondents said they relied on community and voluntary organisations during the pandemic. As previously highlighted, those with mental health issues found themselves somewhat reliant on these external organisations such as the Samaritans. For some, these voluntary and community organisations were a main source of news and information about COVID-19. Focus group attendees mentioned various charities and groups that had been helpful in keeping them updated; *"It was through Dementia NI that I found out about the jab…"; "Crohn's & Colitis UK provided excellent, tailored information…"* These quotes outline just a couple of VCSE organisations that were discussed. As seen in **Figure 12**, 28.4% (285/1,006) stated that they accessed information on COVID-19 from community and voluntary organisations. A few respondents said they wanted their GP or other HSC staff they were in contact to directly give them personalised information that was tailored to their condition. This is further detailed in **section 5.4.2.**

Participants also outlined gaps they felt existed in the dissemination of communications and information throughout the pandemic; another key theme from Peoples' Priorities, with one attendee quoted *"Official letters from the chief health officer were a bit useless – by the time they arrived the info in them had long been disseminated in the media."*

In some cases, community and voluntary organisations were the only form of contact and support available to people during the pandemic. This was again particularly apparent for those with mental health issues with focus group attendees referring to *"Action Mental Health"* as their *"only interaction"* and being able to *"speak to AMH online."* The word *"vacuum"* was used by one attendee when describing the lack of communication they had had throughout COVID-19, evidence of how important the role of these VCSE organisations are.

These findings from Peoples' Priorities are both supported by, and support, the internal and external literature. Through the PCC's *"Grief & Bereavement through COVID-19"* project, participants regularly discussed the important role that Marie Curie played in supporting their loved one and the family.[5] Similarly, in The COVID-19 Decade report by the British Academy, community and voluntary organisations are described as having *"demonstrated the importance of community-led infrastructure and resilience…"*[10] This report clearly outlines the crucial role VCSE plays for the short and long-term support of people through COVID-19 and beyond.

5.2.2 Private

Private healthcare providers i.e. those independent of the NHS, have been accessed throughout COVID-19 for a variety of reasons. In the Peoples' Priorities survey, 24.2% of people (n=128/529) indicated that they had accessed private HSC since March 2020; 60 of which stated explicitly that this was a result of COVID-19. For many, the main reason for going private was the long waiting lists they were facing through the NHS. One respondent detailed that they would be waiting for a CT scan for 3 months through the NHS and this was why they opted for private healthcare. Others felt they had no other choice; *"[The] waiting lists [are] so long that I was forced to access private care."*

A sense of frustration could also be seen through some responses in relation to the affordability of these services. Many felt that could they afford to access private healthcare then they would do so, but they believed that NHS providers were contributing to the problem; *"I think it's ridiculous that an orthopaedic surgeon can cancel all his NHS work but still remain available privately at a private clinic."*

> *"why are doctors able to still provide service in the private sector but not for NHS?"*
>
> **Female, survey respondent**

In the 2016 Peoples' Priorities report, waiting lists was again noted as the reasoning for some people choosing private healthcare; "*I have been told I would wait for over a year on the waiting list and I would say that I will now use my private healthcare."*[28] This unhappiness with waiting lists is reflected in the complaints being received across the five Health & Social Care Trusts, as well as by the Client Support team within the PCC, with waiting times appearing as a complaint across both GP and A&E services.

5.3 Treatment Timelines

5.3.1 Delay to treatment

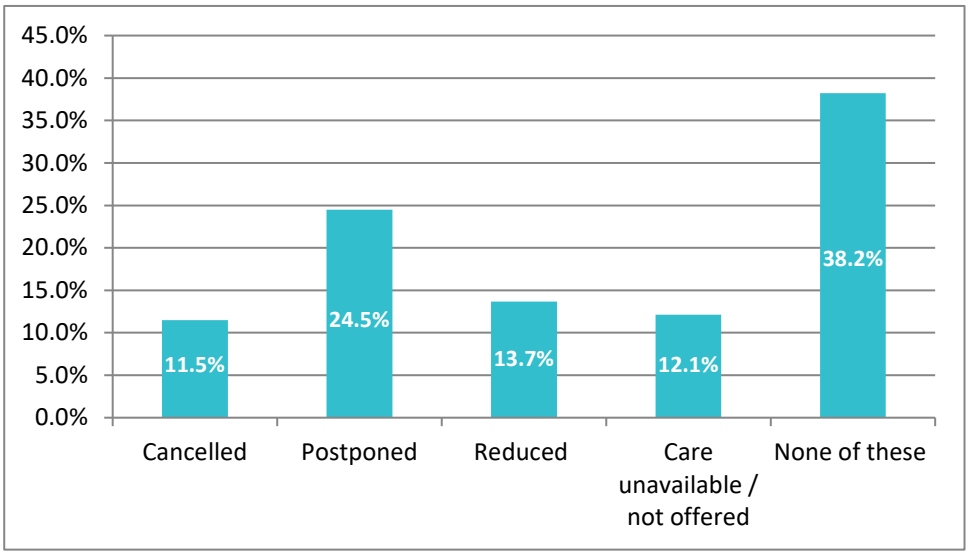
Figure 8 shows that of the respondents, 61.8% (n=754/1220) indicated that their health or social care was cancelled, postponed or reduced since March 2020. When asked if the reason given for this was the COVID-19 pandemic, 80.5% (n=430/534) said yes. The HSCB revealed that 180,000 people have waited longer than 52 weeks for their first outpatient appointment as of January 2021. A further 61,075 people have been waiting for an elective inpatient or day case treatment for over a year.[29]

Around 18% (n=80/448) stated there was no or very little impact as a result of these delays. However, this leaves almost 36.6% (n=369/1008) of total survey respondents who had suffered the impacts that delays to HSC bring.

Respondents to Peoples' Priorities said that they were told due to COVID-19 their appointments had been delayed as they were not seen as a *"priority",* or *"urgent".* Some respondents said they were told that they couldn't be seen because of COVID-19 restrictions; *"I was due to go for brain surgery on 24th March but was postponed until May 2020 due to COVID-19…"* Others felt that the reasoning for their waiting time was down to the Trust wanting reduced numbers of people at HSC sites; *"[The] Trust wanted fewer people coming into its premises."*

[29] Smyth L. *Alarming rise in NI patients left waiting more than a year for hospital appointments. https://www.belfasttelegraph.co.uk/news/health/alarming-rise-in-ni-patients-left-waiting-more-than-a-year-for-hospital-appointments-40363325.html (accessed 6 May 2021).*

Figure 8: Graph showing the percentage of respondents who had their health and social care cancelled, postponed or reduced since March 2020



Respondents to Peoples' Priorities shared the impact that waiting times had on them. In a 2018 report on waiting lists, the most common resulting impact on health was increased pain for over a third of participants (n=111), followed by a negative impact on mental health (n=32).[30] This poor mental health was often attributed to living in pain and the uncertainty invoked by wait times. Similar to2018 findings respondents to the Peoples' Priorities work in 2020/2021 reported that long waits for appointments affected both the physical and mental health of many, with descriptors such as *"unhappy", "worried", "concerned", "isolated", "stress" "neglected"* and *"abandoned"* being used to describe how waiting times made them feel.

[Around] 22% (n=99/449) of those who discussed the impacts of delays told us that they had been left in physical pain and that their health had deteriorated as a result of waiting; *"I have been in pain and not having my appointments has been detrimental to my health."* Some also relayed their concerns about their longer-term health and the ways that delays had negatively impacted this for example one respondent outlined having to *"resort to potentially long-term reliance on pain killers"* as their pain had worsened while awaiting treatment.

Furthermore, 10.3% (n=36/351) respondents said that mentally having been on a list for so long had caused them to become stressed and made their anxiety increase. This was also a common impact of delays, affecting around 17% (n=76/449) of respondents. Given the extensive literature acknowledging the impact of the pandemic on mental health and wellbeing, it is clear that stressors exist both within and outside of Health & Social Care; *"[My] progressive disease is progressing*

[30] Patient and Client Council (2018) *Our lived experience of waiting for healthcare*, PCC, Belfast

without available treatment, [it's] caused worsened symptoms and effects on mental health." Respondents noted a sense of uncertainty that delays had caused around their health and conditions, which had not been checked or managed as a result.

The financial implications of waiting lists is evident too through those respondents who have ended up paying for private HSC to try and avoid extensive wait times; *"I have nearly lost my career through sickness waiting on surgery and in the end, I have had to go private."*

As stated earlier in **Section 5.2.2,** in the survey, 24.2% (n=128/529) indicated that they had accessed private health or social care since March 2020, and of these respondents, sixty said that this was because of the COVID-19 pandemic. Given the socioeconomic considerations at play in relation to the accessibility of private healthcare, as outlined by the British Academy[10], it is feasible that many of those faced with long waiting times without access to private healthcare represent the most in need and lower socioeconomic classes of our society.

Figure 9: Word cloud of free text codes of responses to question 45, 'what impact did changes / delays have on respondents, if any?'

5.3.2 Waiting lists

Long waiting lists are an ongoing issue and were highlighted in Peoples' Priorities reports. Waiting times across all HSC services was a top priority identified in 2016[28], the second top priority in 2014[31] and third top priority in 2011[32]. Furthermore, waiting list data from Client Support database indicated that waiting list delays and cancellation was the fourth largest area of concern from April 2020 – March 2021.

> *"I've been waiting to see my dentist. I haven't heard a thing. I was due for treatment pre covid … I had an appointment in for June but this was cancelled … I would like to know what's going on."*
>
> **Male, Survey Respondent**

Respondents to this work in 2020/2021 felt that COVID-19 has intensified this issue. This issue is reflected across the five HSC Trusts in Northern Ireland; in each of their annual complaints reports, waiting times have been a top area for complaint. The Trusts attribute this to the direct impact of COVID-19, although from previous reports, as well as the Access to GP report[9], it is evident that waiting lists have been an ongoing issue.

Some respondents told us that they felt COVID-19 was being used as the *"great excuse"* now for why the waiting lists are so long, when this is an issue that's been going on far longer than the pandemic; *"Northern Ireland was already bad, [it's] even worse now. The waiting lists are long and I don't expect to be seen…"*

Respondents expressed that they were disappointed with how long they had to wait for an appointment, with one respondent sharing their mother will have had to wait 5.5 years before receiving surgery she is in need of. Others who were due to have an appointment before March 2020 and have now had these delayed or cancelled also expressed their dismay and indeed their lack of understanding or information as to why this was the case; *"I had an appointment in for June but this was cancelled… I would like to know what's going on."*

Whilst some of the respondents said that they had since got a new appointment, some had still heard nothing, and have been waiting for more than a year to be seen, with one focus group respondent waiting *"117 weeks for a review that was supposed to happen in March."*

Whilst the public understand the pressures that HSC services have faced as a result of COVID-19; this does not remove the desire to receive the care they need; *"I understand the pressures, but still it's affecting me."* In a report produced by the

[31] Patient and Client Council (2014) *The Peoples' Priorities, 2014*, PCC, Belfast.

[32] Patient and Client Council (2011) *The Peoples' Priorities, 2011*. PCC, Belfast.

Department of Health, 167,806 patients have waited over 52 weeks for an outpatient appointment; 53.5% of patients are waiting over 52 weeks for inpatient or day case treatment; and 40% of patients are waiting >26 weeks for a diagnostic test.[33]

As previously highlighted, for a small proportion of respondents, 24.2% (n=128/529) over 1/10 of the respondents to the survey, the long wait resulted in them making the decision to access private healthcare; feeling *"fed up"* and being in *"unbearable"* pain leading to these decisions. Again, the accessibility of private healthcare must be taken into consideration and some respondents (n=6) have queried why private services aren't being used more widely to address the waiting list problem; *"They should be opening private hospitals for cancer referrals."* It is important to note that cancer surgery has been performed in some private hospitals throughout the pandemic.

It is important to note that throughout the survey, focus groups, and indeed across the caseload of the PCC terms such as *"postponed", "cancelled"* and *"reduced"* are used. Even if the term *"waiting lists"* has not been explicitly mentioned by respondents, those aforementioned terms are alternatives, and lead to discussion around the same situation i.e. patients not having access to their care when they feel they need it. Feedback suggests that treatment timelines across the Trusts are an area of concern for the general public, which have not emerged as an issue in the last 12 months, but rather have been exacerbated by the COVID-19 pandemic. This has been an issue which respondents of Peoples' Priorities have been identifying since 2011[32] and which has yet to be handled conclusively.

5.4 Information Provision

5.4.1 Communication Methodologies

Respondents spoke to us about issues with communication. Not everyone found changes to how appointments were conducted an easy process. For some attending an appointment alone was a stressful experience and they wished they could bring someone in with them to their appointment for moral support – *"I go alone to my treatments, which isn't always great when you're feeling anxious!"*

This lack of support was felt across other project groups also. For those who participated in the Grief and Bereavement project[5], there were frequent reports of their loved one feeling distressed and confused when attending appointments on their own, preventing them from relaying the correct information to their family. Focus group attendees from the Dementia group for Peoples' Priorities also suggest that patients may prefer to have appointments *"when a family member is present."*

[33] Department of Health; *Hospital Waiting Times Key Statistics,* 2020

Within the sign language focus groups, respondents spoke about the difficulty of not having face to face appointments and the difficulties in adapting during COVID-19. Again, this was a theme which emerged through other pieces of work namely the HSCB Remote Interpreting Services project[7]. Of those who used the Interpreting apps generally they said they were useful. However, there were some issues with them, namely the availability of interpreters. Availability raised issues surrounding the timing of appointments – *"it depends on when the interpreters are working and you just have to wait until they are available"* - as well as the provision of either a British or Irish sign language interpreter. Internet signal is required to access these services and again posed another barrier during appointments, with patients referring to the *"poor WiFi"* in hospitals and the complete lack of WiFi in COVID-19 test centres.

Particularly in emergency situations, the use of interpreting apps introduces difficulties. This was brought to light through the HSCB Interpreting project[7], with participants highlighting the time spent waiting for an interpreter as a barrier to app usage. Through Peoples' Priorities the availability in emergency situations was again highlighted as an issue – *"… access to an interpreter in an emergency or short notice was not available."*

While the provision of PPE was a source of stress and anxiety for HSC professionals, this has introduced different problems for those who are deaf. Some respondents spoke about the difficulty of understanding staff when they were wearing face masks; both with regards to interpreters and medical professionals. Again, this echoes the findings of the HSCB Remote Interpreting Services project, with Deaf service users expressing their desire for clear face masks to be worn to aid communication, as well as their safety concerns when masks were removed to try and aid lip-reading.[7]

> *"[I] Brought phone to appointment to use interpreting service but when the time for the appointment came there was no interpreter."*
>
> **Female, focus group respondent**

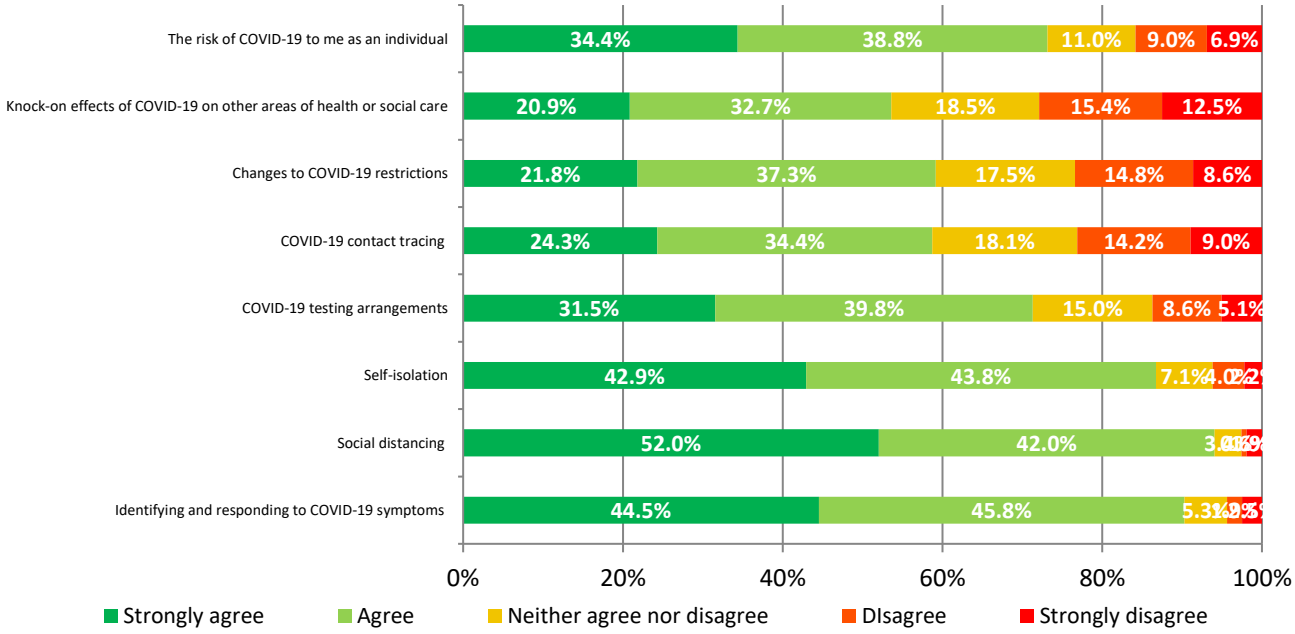
Furthermore, some respondents spoke of their frustration as a result of HSC staff calling their phones instead of using text or video calls. This was especially frustrating as they felt staff should have known they were Deaf and that this was not an appropriate way to communicate with them. Deaf awareness is an important issue highlighted by respondents and reiterates findings from other work, with respondents giving examples of health professionals frequently trying to call-back Deaf patients to arrange appointments[7]; something we heard again through Peoples' Priorities discussions – *"They* [GP] *said they called the landline, but I told them they should have called my mobile as I'm deaf…"*

Communication methodologies prove to be an important consideration for those who are Deaf, but as highlighted in the HSCB Interpreting Services report, this is also true for those who are Deafblind, blind, and those with acquired hearing loss[7] – groups who are under-represented through the Peoples' Priorities survey and focus groups.

5.4.2 Information Provision

As seen from **Figure 10** there was variation in how well-informed people felt about different aspects of COVID-19.

Figure 10: Graph showing to what extent respondents felt informed about information and regulations regarding COVID-19



Of the Peoples' Priorities respondents, 27.9% (n=270/968) said they did not feel well informed about the knock-on effects of COVID-19 on other areas of HSC. A similar proportion, 23.4% (n=225/962), said that they did not feel well informed about changes to the COVID-19 restrictions.

On the other hand, 90.3% (n=866/959) agreed or strongly agreed that they were well informed in identifying and responding to COVID-19 symptoms, and 94.0% (n=920/978) agreed or strongly agreed that they were well informed about social distancing – *"I feel I have been sufficiently informed."* In general, well established population-level guidance (e.g. on social distancing, self-isolation and symptoms) seemed to be well understood but people reported feeling less sure about aspects of COVID-19 which were newer or more 'fluid', or which didn't apply to everyone.

It is useful to reflect on this response in comparison to the findings from the Shielding Survey[6], where many people shielding in Northern Ireland appeared to prioritise being kept informed above other areas of unmet need. There was a strong desire to be given clear guidance on what they should and should not do.[6] There were also clear messages that people wanted to see and understand any available information on COVID-19 infection rates – ideally at as localised a level as possible – and on the actual risk posed to them as individuals. Respondents expected that having access to this information would empower and support them to make their own informed decisions about whether and how to emerge from shielding.

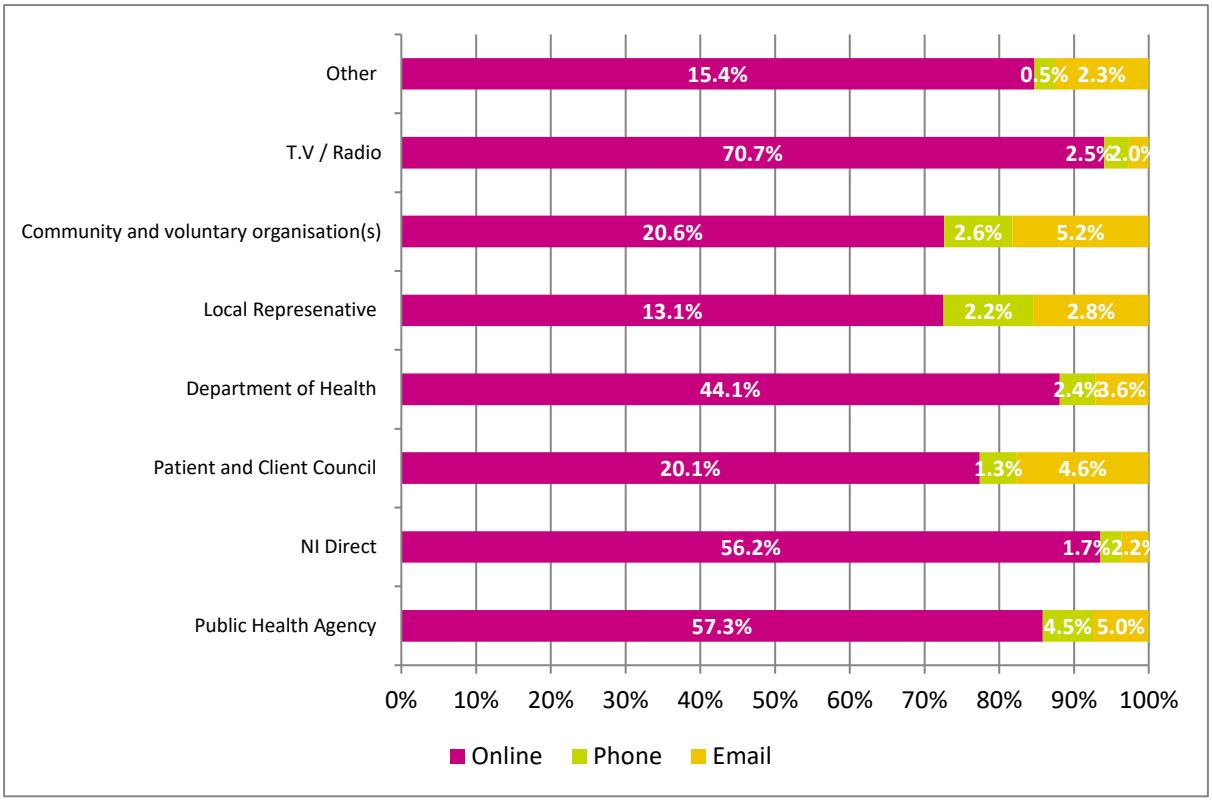
Respondents were also asked to what extent they agreed that information on COVID-19 was accessible to them. 79.2% (n=752/950) agreed or strongly agreed that information about symptoms, testing & self-isolating has been accessible, as this has been repeated across multiple platforms & hasn't changed too much. Nonetheless for some, the frequency of guidance and regulations changing was reportedly confusing, and difficult to keep up with, with particular focus on restrictions and isolation periods. Others felt that those with chronic conditions were not updated appropriately with one respondent suggesting they needed *"specialist advice and to be kept well informed so that they do not have anxiety or stress…"*

Figure 11: Word cloud of free-text codes of responses to the question 51, 'did respondents have anything else to add with regards to information from HSC organisations during the COVID-19 pandemic?'

Respondents reported using different sources to access information related to COVID-19, for example symptoms and regulation changes. As can be seen from

Figure 12, most have been utilising online resources to gather their information on COVID-19. Many used government websites such as gov.uk, the Department of Health and NI Direct, as well as agencies like the PHA and PCC.

Figure 11: Graph showing where respondents accessed information on COVID-19



Some respondents said their main source of information were social media sites, often looking at HSC or voluntary organisation content for news. The most mentioned social media was Twitter, followed by Facebook. In addition, others said they watched the news on TV and government briefings - *"There is lots of information on the TV, the newspaper and social media."* Those in the deaf community appreciated that there were interpreters at these briefings also, describing the presence of interpreters as *"useful".* For some, they said their main source of news was a family member who worked with HSC services, described as *"a clear line of information"* by one respondent.

On the other end of the spectrum, some respondents told us that they had stopped keeping up with the news as it made them anxious and that the amount of information and changing guidance was at times confusing to keep up with. They described themselves as feeling *"very overwhelmed"* and *"confused"* by the quantity and fluidity of COVID-19 information with one focus group attendee expressing *"You're never 100% sure about what is happening."* External literature reiterates this idea of fatigue induced by the amount of COVID-19 coverage[10]. In this research it is also accepted that many have chosen to avoid news related to the pandemic, and

distrust in the media is outlined as a possible reason for this, with trust in news organisations falling in the UK from 57%-45% between April and August 2020.[10]

A few respondents wished their GP or other HSC staff they were in contact with would directly give them information, as they would feel more reassured that they were getting the right information – *"I'd rather get it [information] from my GP directly."*

It was reported that the disparity in regulations between the UK and Republic of Ireland introduced further confusion when respondents were trying to keep up with information. For those in border communities or who were required to frequently travel to the UK, this lack of clarity was hard to deal with – *"what was a rule for one was not for the other."* Given the positioning of Northern Ireland, the additional confusion of broadcasts from both Westminster and Stormont may have led people to social media platforms for clarification; a source which was described by the British Academy as having "serious issues related to the circulation and consumption of misinformation."[10]

5.5 Fear of Accessing Services

Many respondents expressed that they avoided using HSC services during the pandemic, as they didn't want to be a *"burden"* on already stretched services. According to the British Academy, in the first 19 weeks of the pandemic in the UK, 1 in 5 people did not tell their GP about their physical health when they ordinarily would have done so[10]; clear examples of this exist in the Peoples' Priorities responses also with some respondents stating that they did not attend their GP for certain conditions. These range from heart conditions to cuts. Respondents stated that a feeling of *"social pressure"* contributed to this non-attendance.

Research conducted by Queens University Belfast has reported initial findings that the fear of becoming infected with COVID-19 has been having an impact on peoples' mental health[18], specifically for those who have been in isolation and would have a heightened fear of venturing out to access HSC services. It is evident that fear plays an important factor in the utilisation of HSC services now, and moving forward into post- pandemic times.

Furthermore, some respondents said that they avoided using HSC services as they were afraid they would contract COVID-19 whilst in a HSC setting – *"people in general don't want to go because they are afraid… [to] catch COVID-19."* Data from within the PCC shows that concerns around appropriate infection control have been raised by members of the public via the Freephone number and Client Support services, with 1 in 3 safety related calls specifically originating around infection control measures.[8] This is reiterated by members of the Deaf community who,

through the HSCB Remote Interpreting Services project, detailed the fear they felt when some HSC staff would remove their face masks to try and communicate with them, making them susceptible to COVID-19 being passed on[7]. This is also quoted as a problem within the COVID-19 decade paper produced by the British Academy, suggesting people are avoiding medical services *"in fear of catching the virus"*, which may have a subsequent impact for future pressure on HSC.[10]

However, for those who did attend an appointment, the majority of respondents said that they 'felt safe' when they were there. Respondents felt that the guidelines, such as social distancing and the use of PPE were being adhered to by HSC staff – *"all protocols are there, masks, sanitiser and distance."*

5.6 Would they be happy for things to continue this way?

For many, COVID-19 has illustrated the importance of face to face interactions and physical contact. For some, they believe it correlates to a higher standard of care, while for those involved in the Grief & Bereavement project, this face to face contact, body language and physical interaction has proven to be vital for coping with grief and bereavement, minimising feelings of isolation, and for mental health.[5] The suggestion for a blended approach to services rings true across the findings of Peoples' Priorities, with an underlying understanding of the varying needs, abilities, and privileges of the people served by our HSC system seen as critical in determining which approach suits the individual best.

Although people appreciated the pressures that Health & Social Care services were under, and that in most cases staff were doing their best to see and accommodate people, some people still wanted to see the return of face to face consultations. Just under a third (32.2%, n=75/233) stated that they were not happy for services to continue in the way they were now being provided expressing the need or preference for face to face appointments and treatments. They cited reasons such as getting to know medical professionals better and not missing symptoms.

However, it is important to note that just over two fifths (43%, n=241/559) said they would be happy to continue using services in their new format. Over one third (n=341/1008) of total survey respondents discussed a movement to phone appointments, consultations or triage systems. The suggestion of a *"better triage system"* was also noted.

Respondents told us that some GPs moved to ordering scripts online. Most people were happy with this change as they didn't have to call up their surgery anymore, therefore they were not wasting time waiting to speak to someone about their repeat prescription.

Online prescriptions are seen to be *"much more efficient and effective"* by some as well as being *"an easier service to access".* However, it should be noted some respondents had this service available pre-pandemic, and in a few cases this service was now cancelled due to the pandemic. Variations across service providers in different areas again emerging as a theme here.

Our work also highlighted that consideration must be given to the accessibility of a move to online provision for elderly populations or those with disabilities as expressed through the HSCB Remote Interpreting Services project[7]. The research conducted by the British Academy also acknowledges that many people, over the age of 65 had not used the internet prior to the pandemic (29% in the UK).[10]

6 Conclusions

6.1 Peoples' experiences of using HSC services during the COVID-19 pandemic

Healthcare systems across the UK were under pre-existing pressures prior to the COVID-19 crises; acute staff shortages, lengthy waiting lists, increasing patient demand and significant budget deficits have been intensified by COVID-19 and, unsurprisingly, satisfaction with HSC services fell during the pandemic.

This report, and the concurrent data from advocacy services within PCC and our other engagement work, shows that the provision of GP services, the manner in which they were offered, and the interactions service users had with their respective GP surgeries have been a source of concern for many in Northern Ireland over the past 12 months. Respondents said they found it difficult to access services as they had a long wait to be seen and there was poor communication from GP surgeries, particularly when it came to routine appointments. During the pandemic, GPs employed telephone systems to try and manage appointments and care, which is met by both positive and negative feedback from the public. With GP referrals down by 58% between March-May 2020, this delay will have a ripple effect over time and service provision in the coming twelve months.

Of note is the impact on future use of the HSC services. During the pandemic, one in five people did not tell their GP about their physical health when they ordinarily would have done so[10]; either to avoid being a *'burden'* on the system, social pressures to prioritise the *'most ill',* or because they were afraid they would contract COVID-19 whilst in a HSC setting.

In A&E, some people described delays, long waits and poor information received at their local A&E. The majority described staff as kind, busy, pleasant, caring and wonderful in some cases. The link between the care received and COVID-19 has been acknowledged by many with respondents appreciating the level of care *"given the circumstances."*

Telehealth provision for mental health was deemed inappropriate by two in three people. Respondents expressed dismay at the lack of alternative services, with the focus instead on medications. The resultant psychological distress that those in isolation face may contribute to the number of complaints to the PCC in April and May 2021 as mental health needs rise and the system for processing referrals tries to meet demand.

6.2 The consequences of COVID-19 for peoples' routine / scheduled healthcare and social care

Three in five people reported experiencing cancelled, postponed or reduced service from March 2020 with 180,000 people waiting more than one year for outpatient appointments. For some, long waits for appointments affected their physical and mental health, however, one in five stated there was no or very little impact as a result. For those who were adversely impacted, some felt that knowing why their appointment was delayed, and when it might happen, would have helped. This will be an important consideration when setting waiting list targets and the criteria for prioritising patients.

One in four stated they could afford private healthcare and pursued this opportunity, mitigating the impact of HSC service delays. Many felt that, could they afford to access private healthcare then they would do so, but that they thought NHS providers were contributing to the need to do so; *"I think it's ridiculous that an orthopaedic surgeon can cancel all his NHS work but still remain available privately at a private clinic."* Those faced with long waiting times without access to private healthcare represent the most in need and lower socioeconomic classes of our society.

6.3 Peoples' levels of satisfaction with the restrictions imposed on 'normal' HSC services due to COVID-19

Although people appreciated the pressures that Health & Social Care services were under, and that in most cases staff were doing their best to see and accommodate people, they still wanted a return to face to face services. Online repeat prescription renewal processes were reported to be *"much more efficient and effective"*. The accessibility of this for elderly populations or those with disabilities must also be considered however. A blended approach to services with an underlying understanding of the varying needs, abilities, and privileges of the people served by our HSC system would be welcome.

6.4 The extent to which people feel that they have been adequately informed on how to keep themselves (and the wider population) safe and healthy

Information provision fell into two categories; information about COVID-19 and information about routine health matters.

People stated they felt adequately informed on how to keep themselves safe and healthy. Almost three quarters of people understood the risk of COVID-19 to them as individuals and just over half appreciated the knock-on effects of COVID-19 on HSC services. Three out of five people understood the changes made to COVID-19 restrictions as they were made and how Contract tracing would help. Four in five people felt information about symptoms, testing & self-isolating has been accessible as this has been repeated across multiple platforms. Most accessed the messages on TVs / Radios from PHA. Given the positioning of Northern Ireland, the additional confusion of broadcasts from both Westminster and Stormont may have led to a greater reliance on social media platforms for clarification.

Not everyone found changes to how appointments were conducted an easy process and this may have resulted in lower retention of information by those who would normally attend with someone else. The difficulty of not having face to face appointments, complications in relying on interpretation services set up during the pandemic or overburdened as a result of it, led to perceptions of ‘inaccessible’ health care that added to ongoing medical concerns.

7 Recommendations

The issues facing GPs regarding access, waiting times, securing referrals and attending recurring medical appointments, e.g. diabetic clinics, should be further explored particularly in the context of pressures on services. PCC will reach out to RCGPNI, BMA and GP Federations as well as GP Forums in each HSCT to test the validity of the findings in this paper and to explore options to address. Broader engagement with the public, promoted in a partnership way, to assess the publics' perception of GP services and invite their views on how to improve, where necessary, the patient experience of GP services in N.I. may be helpful.

Consideration should be given to when face to face appointments would be most appropriate in Primary Care settings, should COVID-19 restrictions continue. For those with mental health and terminal illness appointments, digihealth posed an unnecessary barrier. Additionally, in these situations, where people are exempt under government guidelines from wearing a mask indoors, this should be accommodated.

The Minister has released an Elective Care Framework to tackle waiting lists. This report further evidences that the five-year plan to reduce the backlog of patients currently waiting for assessment and treatment, requiring £707.5 million of additional investment to ensure that no patient waits more than a year for assessment or treatment, is needed and timely. It will be necessary for this to consider the HSC workforce given the potential for burn out, trauma and redeployment within the workforce as a result of Covid.

Given the risk of burnout, especially among junior doctors, consideration should be given to a public awareness raising campaign that helps the public understand how to set realistic expectations of their GP and develops a consciousness of when to use a GP, A&E or a pharmacist based on their ailment. Furthermore, a framework for supporting the mental health of frontline workers would be beneficial to ensure the longer-term sustainability of the health service.

Patients can see the benefit of some primary care services moving to online / telehealth platforms, e.g. ordering prescriptions, booking routine appointments at recurring clinics (e.g. diabetes, M.S.), and consideration could be given to evolving digihealth products and platforms with patient involvement.

Service User involvement and feedback should continue to inform the ongoing development, implementation, and continuous improvement of all aspects of the HSC service. To this end, and given the areas of concern highlighted within this report, PCC will establish Engagement Platforms with a focus on Mental Health, Learning Disability, Care of Older People, amongst others.

The PCC is committed to co-design and increasing the participation of the public in the work we do. This includes increasing diversity in our engagement work and reaching out to groups that are more marginally represented in HSC engagement.

To this end, PCC will seek to collect section 75 data on its' members and actively campaign to diversify this group. We will also seek to address how we collect data, using more easy read formats, signed videos, and utilising interpreting services where possible.

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9 Appendices

9.1 Survey

9.1.1 Standard

Patient and Client Council - COVID-19 People's Priorities Survey

The COVID-19 pandemic had major impacts on health and social care in Northern Ireland during 2020. The Patient and Client Council are keen to hear how the pandemic has affected your healthcare or social care, and how appropriate and effective you feel the Health and Social Care (HSC) response to COVID-19 has been. We're engaging with the public through this survey in an effort to understand:

- People's experiences of using HSC services during the COVID-19 pandemic;
- The consequences of COVID-19 for people's routine / scheduled healthcare and social care.
- People's levels of satisfaction with the restrictions imposed on 'normal' HSC services due to COVID-19; and
- The extent to which people feel that they have been adequately informed on how to keep themselves (and the wider population) safe and healthy.

The survey aims to evaluate the HSC response to COVID-19 to date, from the perspective of service users. This will allow the PCC and other HSC organisations to:

- Learn what people think has worked well, or not so well; and to
- Use this learning to adapt better to COVID-19 in future, and particularly to inform decisions around 'restarting' HSC services during 2021.

After the survey closes in early 2021, response data will be analysed and written up in a report. This report, including recommendations based on the findings, will be published online and shared directly with other HSC organisations (e.g. Dept of Health, HSC Trusts). Findings will be reported in a way that will avoid identifying individuals or their responses. Your responses to the survey will remain anonymous throughout, and will be securely stored and password protected at all times. If you wish to withdraw your response after submitting it, please contact Laura O'Neill Laura.ONeill@pcc-ni.net and and we will do all we can to find and delete your response.

To begin, please click 'Next' below and follow the onscreen instructions. The survey will take approximately 10 minutes to complete. Please note that you will only be shown the questions that are relevant to you based on your responses so some question numbers may be skipped. Contact info.pcc@pcc-ni.net at if you have any questions or queries.

Alternatively you can:

- Download the questionnaire from our website here, print it, complete it and return it to us by email - Laura.ONeill@pcc-ni.net - or post to FREEPOST, Patient and Client Council;
- Complete the survey over the phone by calling our Freephone number on **0800 917 0222**; or
- Participate in a facilitated online group session

Q If you would like to take part in an online group session, please provide your name and email address for us to contact you at a later date.

We greatly appreciate your contribution to this survey.

Section 1 - Demographics

Q1 Are you answering for yourself or on behalf of someone else?

- Myself — Go to Q29
- Someone else — Go to Q2

Q2 What is their relationship to you?

- Parent
- Child
- Partner/Spouse
- Friend
- Other

Please specify

Please answer the following questions based on the person on whose behalf you are completing the survey

Q3 Which gender do they identify as? (Please select one option only)

- Male
- Female
- Other
- Prefer not to say

Please specify

Q4 Which age group applies to them? (Please select one option only)

- ◯ 0-17
- ◯ 18-24
- ◯ 25-34
- ◯ 35-44
- ◯ 45-54
- ◯ 55-64
- ◯ 65-74
- ◯ 75-84
- ◯ 85+
- ◯ Prefer not to say

Q5 What is their ethnic group?

- ◯ White
- ◯ Black- Caribbean
- ◯ Black - other
- ◯ Chinese
- ◯ Indian
- ◯ Pakistani
- ◯ Irish Traveller
- ◯ Mixed ethnic
- ◯ Other
- ◯ Prefer not to say

Please specify

Q6 Do they consider themselves to have a disability?

- ◯ Yes
- ◯ No

Q7 What is their postcode?

Q8 From which Health and Social Care Trust do they normally receive health or social care?

- ◯ Belfast
- ◯ Northern
- ◯ South Eastern
- ◯ Southern
- ◯ Western
- ◯ Don't know

Section 2 - Treatment and Care

Q9 Have they, the service user, accessed Health and Social Care services since March 2020?

- ◯ Yes — Go to Q14
- ◯ No — Go to Q17

Q10 Which Health and Social Care service area have they come in contact with most frequently since March 2020? Please choose one option only.

- ◯ Accident & Emergency
- ◯ Allied Healthcare (e.g. Physiotherapy, Occupational Therapy, Speech and language Therapy, Dietician)
- ◯ Children's
- ◯ Dental
- ◯ Disability
- ◯ Domiciliary Care (e.g. carer coming into home)
- ◯ Elderly
- ◯ Family and Childcare
- ◯ Gastroenterology (diagnoses and treats disorders of the digestive system)
- ◯ GP
- ◯ GP Out of Hours
- ◯ Maternity
- ◯ Mental Health
- ◯ Oncology (Cancer services)
- ◯ Orthopaedics (diagnoses and treats disorders of the bones, joints, ligaments, tendons and muscles)
- ◯ Palliative Care
- ◯ Pharmacy
- ◯ Residential & nursing homes
- ◯ Social Care
- ◯ Social Services
- ◯ Surgery
- ◯ Other - Please specify

Please specify

Q11 Was this contact due to suspected / confirmed COVID-19?

- ◯ Yes
- ◯ No
- ◯ Don't know

Q12 Thinking about the service they used most frequently, to what extent do they agree they were satisfied with the service provided?

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
○	○	○	○	○

Please explain why:

Q13 Again thinking about the service they have used most frequently, has the way they access this service changed since March 2020? E.g. Telephone or virtual appointments

- ○ Yes, it has changed
- ○ No, it has not changed

Please explain how?

Q14 Was the reason given for this related to the COVID-19 pandemic?

- ○ Yes
- ○ No
- ○ No reason was given

Q15 Would they be happy to continue using the service in this way?

- ◯ Yes
- ◯ No
- ◯ Don't know

Please explain why

Q16 Thinking about their most recent contact with the Health and Social Care service identified previously, to what extent do they agree with the following statements?

	N/A	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
a) The length of time I waited for the appointment / visit was reasonable	◯	◯	◯	◯	◯	◯
b) I was told beforehand what to expect (e.g. what to do or where to go) during the visit / appointment	◯	◯	◯	◯	◯	◯
c) During the appointment / visit, I was given enough information about what to do or where to go	◯	◯	◯	◯	◯	◯
d) Staff were compassionate	◯	◯	◯	◯	◯	◯
e) Staff took time to listen to me	◯	◯	◯	◯	◯	◯
f) Staff adhered to social distancing advice	◯	◯	◯	◯	◯	◯
g) Staff used adequate Personal Protective Equipment (PPE)	◯	◯	◯	◯	◯	◯
h) I felt safe during the appointment / visit	◯	◯	◯	◯	◯	◯
i) My health or social care need was adequately met	◯	◯	◯	◯	◯	◯

Q17 Have they had any health or social care (including tests, investigations, treatment, surgery or routine care) cancelled, postponed or reduced since March 2020? Select all that apply

- [ ] Cancelled
- [ ] Postponed
- [ ] Reduced
- [ ] Care unavailable / not offered
- [ ] None of these

Go to Section 4

Q18 Was the reason given for this related to the COVID-19 pandemic? If more than one area of their care has been affected, please answer based on the care they see as most essential.

- ◯ Yes
- ◯ No
- ◯ No reason was given

If so, please give details below

Q19 What impact did this have on them, if any?

Q20 Have they received any private healthcare or social care since March 2020

- ◯ Yes
- ◯ No

Q21 Was this due to the COVID-19 pandemic?

- ◯ Yes
- ◯ No

Section 3 - Experiences of Health and Social Care during COVID-19

Q22 Do you have any further comments about their experience of Health and Social Care during the COVID-19 pandemic?

Section 4 - Information Provision

Q23 On a scale 1-5, 1 being 'Strongly disagree', and 5 being 'Strongly agree', to what extent do they agree with the following statements?

'I feel that I have been well informed about...

	N/A	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Identifying and responding to COVID-19 symptoms	○	○	○	○	○	○
Social distancing	○	○	○	○	○	○
Self-isolation	○	○	○	○	○	○
COVID-19 testing arrangements	○	○	○	○	○	○
COVID-19 contact tracing	○	○	○	○	○	○
Changes to COVID-19 restrictions	○	○	○	○	○	○
Knock-on effects of COVID-19 on other areas of health or social care	○	○	○	○	○	○
The risk of COVID-19 to me as an individual	○	○	○	○	○	○

Q24 To what extent do they agree that information on COVID-19 has been accessible to them?

N/A	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
○	○	○	○	○	○

Q25 Please explain your answer

Q26 Where have they accessed information on COVID-19? Please select all that apply. Please select all that apply.

	Online	Phone	Email
Public Health Agency	☐	☐	☐
NI Direct	☐	☐	☐
Patient and Client Council	☐	☐	☐
Department of Health	☐	☐	☐
Local representative	☐	☐	☐
Community and voluntary organisation(s)	☐	☐	☐
T.V / Radio	☐	☐	☐
Other	☐	☐	☐

Q27 If other, please state where they accessed information on COVID-19?

Q28 Do they have anything else to add with regards to information from Health and Social Care services during the COVID-19 pandemic?

Please go to Section 5 at the end of the survey

Q29 Which gender do you identify as? (Please select one option only)

- ◯ Male
- ◯ Female
- ◯ Other
- ◯ Prefer not to say

Please specify

Q30 Which age group applies to you? (Please select one option only)

- ◯ 0-17
- ◯ 18-24
- ◯ 25-34
- ◯ 35-44
- ◯ 45-54
- ◯ 55-64
- ◯ 65-74
- ◯ 75-84
- ◯ 85+
- ◯ Prefer not to say

Q31 What is your ethnic group? (Please select one option only)

- ◯ White
- ◯ Black- Caribbean
- ◯ Black - other
- ◯ Chinese
- ◯ Indian
- ◯ Pakistani
- ◯ Irish Traveller
- ◯ Mixed ethnic
- ◯ Other
- ◯ Prefer not to say

Please specify

Q32 Do you consider yourself to have a disability?

- ◯ Yes
- ◯ No

Q33 What is your postcode?

Q34 From which Health and Social Care Trust do you normally receive health or social care?

- ◯ Belfast
- ◯ Northern
- ◯ South Eastern
- ◯ Southern
- ◯ Western
- ◯ Don't know

Section 2 - Treatment and Care

Q35 Have you accessed Health and Social Care services since March 2020?

- ◯ Yes — Go to Q36
- ◯ No — Go to Q43

Q36 Which Health and Social Care service area have you come in contact with most frequently since March 2020? Please choose one option only.

- ◯ Accident & Emergency
- ◯ Allied Healthcare (e.g. Physiotherapy, Occupational Therapy, Speech and language Therapy, Dietician)
- ◯ Children's
- ◯ Dental
- ◯ Disability
- ◯ Domiciliary Care (e.g. carer coming into home)
- ◯ Elderly
- ◯ Family and Childcare
- ◯ Gastroenterology (diagnoses and treats disorders of the digestive system)
- ◯ GP
- ◯ GP Out of Hours
- ◯ Maternity
- ◯ Mental Health
- ◯ Oncology (Cancer services)
- ◯ Orthopaedics (diagnoses and treats disorders of the bones, joints, ligaments, tendons and muscles)
- ◯ Palliative Care
- ◯ Pharmacy
- ◯ Residential & nursing homes
- ◯ Social Care
- ◯ Social Services
- ◯ Surgery
- ◯ Other - Please specify

Please specify

Q37 Was this contact due to suspected / confirmed COVID-19?

- ◯ Yes
- ◯ No
- ◯ Don't know

Q38 Thinking about the service you have used most frequently, to what extent do you agree you were satisfied with the service provided?

Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
○	○	○	○	○

Please explain why:

Q39 Again thinking about the service you have used most frequently, has the way you access this service changed since March 2020? E.g. Telephone or virtual appointments

- ○ Yes, it has changed
- ○ No, it has not changed

Please explain how?

Q40 Was the reason given for this related to the COVID-19 pandemic?

- ○ Yes
- ○ No
- ○ No reason was given

Q41 Would you be happy to continue using the service in this way?

- ◯ Yes
- ◯ No
- ◯ Don't know

Please explain why

Q42 Thinking about your most recent contact with the Health and Social Care service identified previously, to what extent do you agree with the following statements?

	N/A	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
a) The length of time I waited for the appointment / visit was reasonable	◯	◯	◯	◯	◯	◯
b) I was told beforehand what to expect (e.g. what to do or where to go) during the visit / appointment	◯	◯	◯	◯	◯	◯
c) During the appointment / visit, I was given enough information about what to do or where to go	◯	◯	◯	◯	◯	◯
d) Staff were compassionate	◯	◯	◯	◯	◯	◯
e) Staff took time to listen to me	◯	◯	◯	◯	◯	◯
f) Staff adhered to social distancing advice	◯	◯	◯	◯	◯	◯
g) Staff used adequate Personal Protective Equipment (PPE)	◯	◯	◯	◯	◯	◯
h) I felt safe during the appointment / visit	◯	◯	◯	◯	◯	◯
i) My health or social care need was adequately met	◯	◯	◯	◯	◯	◯

Q43 Have you had any health or social care (including tests, investigations, treatment, surgery or routine care) cancelled, postponed or reduced since March 2020? Select all that apply

- [ ] Cancelled
- [ ] Postponed
- [ ] Reduced
- [ ] Care unavailable / not offered
- [ ] None of these

Go to Section 4

Q44 Was the reason given for this related to the COVID-19 pandemic? If more than one area of your care has been affected, please answer based on the care you see as most essential.

- ◯ Yes
- ◯ No
- ◯ No reason was given

If so, please give details below

Q45 What impact did this have on you, if any?

Q46 Have you received any private healthcare or social care since March 2020?

- ◯ Yes
- ◯ No

Q47 Was this due to the COVID-19 pandemic?

- ◯ Yes
- ◯ No

Section 3 - Experiences of Health and Social Care during COVID-19

Q48 Do you have any further comments about their experience of Health and Social Care during the COVID-19 pandemic?

Section 4 - Information Provision

Q49 On a scale 1-5, 1 being 'Strongly disagree', and 5 being 'Strongly agree', to what extent do you agree with the following statements?

'I feel that I have been well informed about...

	N/A	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Identifying and responding to COVID-19 symptoms	○	○	○	○	○	○
Social distancing	○	○	○	○	○	○
Self-isolation	○	○	○	○	○	○
COVID-19 testing arrangements	○	○	○	○	○	○
COVID-19 contact tracing	○	○	○	○	○	○
Changes to COVID-19 restrictions	○	○	○	○	○	○
Knock-on effects of COVID-19 on other areas of health or social care	○	○	○	○	○	○
The risk of COVID-19 to me as an individual	○	○	○	○	○	○

Q50 To what extent do you agree that information on COVID-19 has been accessible to you?

N/A	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
○	○	○	○	○	○

Q51 Please explain your answer

Q52 Where have you accessed information on COVID-19? Please select all that apply

	Online	Phone	Email
Public Health Agency	☐	☐	☐
NI Direct	☐	☐	☐
Patient and Client Council	☐	☐	☐
Department of Health	☐	☐	☐
Local representative	☐	☐	☐
Community and voluntary organisation(s)	☐	☐	☐
T.V / Radio	☐	☐	☐
Other	☐	☐	☐

Q53 If other, please state where you accessed information on COVID-19?

Q54 Do you have anything else to add with regards to information from Health and Social Care organisations during the COVID-19 pandemic?

Section 5 - Further Information

Q56 If you would also like to become a member of the Patient and Client Council's Make Change Together movement to further influence and shape the future of health and social care in Northern Ireland please tick the box below and we will be in contact in due course.

- ◯ Yes
- ◯ No

To allow us to contact you again, can you please provide the following details:

Full name:

Email address:

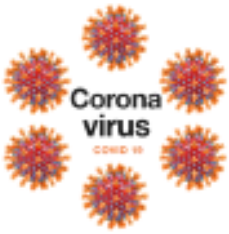
Phone number

Thank you for taking the time to complete this survey.
Please press '*submit*' to send us your response.

9.1.2 Easy Read

Patient and Client Council – COVID 19

People's Priority Survey



COVID-19 has changed care for all of us.

The Patient and Client Council want to hear how it has changed care for you

We want to know what worked well and what didn't work well for you

When you have filled this in, please send it back to:

FREEPOST

PATIENT CLIENT COUNCIL

1

Q1 Are you Male or Female or other?

Male ☐

Female ☐

Other ☐

Q2 What age are you?

20 – 29 ☐

30 – 39 ☐

40 – 49 ☐

50 – 59 ☐

60 – 69 ☐

70 – 79 ☐

Over 80 ☐

2

Q3 Have you used any services since last year? March 2020?

✔ ☐ ✘ ☐

(If No, go to Q8)

Q4 Which ones?

Accident and Emergency / Hospital ☐

Social Worker, Physiotherapist, Occupational Therapist, Speech and Language Therapist etc. ☐

Dentist ☐

Care in your home ☐

Your GP ☐

Day Centre ☐

4

Q5 Tell us how this was different to normal?

Q6 Was this good or bad?

☐

☐

5

Q7 Would you like things to stay this way, or go back to normal?

 ☐  ☐

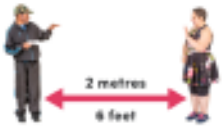
Q8 Were you kept informed about your care?

  ☐  ☐

Q9 Did staff listen to you?

  ☐  ☐

Q10 Did staff stay at a safe distance?



 ☐  ☐

Q11 Did staff use PPE?

Q12 Did you feel safe?

Thank you so much for filling this in. It is very important to hear from you!

9.2 Topic guide

Patient and Client Council - COVID-19 People's Priorities Survey

The COVID-19 pandemic had major impacts on health and social care in Northern Ireland during 2020. The Patient and Client Council are keen to hear how the pandemic has affected your healthcare or social care, and how appropriate and effective you feel the Health and Social Care (HSC) response to COVID-19 has been. We're engaging with the public through in an effort to understand:

- People's experiences of using HSC services during the COVID-19 pandemic;
- The consequences of COVID-19 for people's routine / scheduled healthcare and social care.
- People's levels of satisfaction with the restrictions imposed on 'normal' HSC services due to COVID-19; and
- The extent to which people feel that they have been adequately informed on how to keep themselves (and the wider population) safe and healthy.

This piece of work aims to evaluate the HSC response to COVID-19 to date, from the perspective of service users. This will allow the PCC and other HSC organisations to:

- Learn what people think has worked well, or not so well; and to
- Use this learning to adapt better to COVID-19 in future, and particularly to inform decisions around 'restarting' HSC services during 2021.

After the survey and focus group discussions end in early 2021, response data will be analysed and written up in a report. This report, including recommendations based on the findings, will be published online and shared directly with other HSC organisations (e.g. Department of Health, HSC Trusts). Findings will be reported in a way that will avoid identifying individuals or their responses. Your responses will remain anonymous throughout.

Section	Question	Time
Introduction/Respondent Details	Gather demographic information such as; Gender, Age, carer and or service user, and Trust location.	5-10 minutes or pre meeting
Treatment and Care	Have you/they, the service user, and accessed Health and Social Care services since March 2020? Which Health and Social Care service area have you/they come in contact with most frequently since March 2020?? Was this contact due to suspected / confirmed COVID-19? Thinking about the service you/they used most frequently, you/they satisfied with the service provided? • Please explain why: Again thinking about the service you. they have used most frequently, has the way you/they access this service changed since March 2020? • Prompt E.g. Telephone or virtual appointments • Please explain how Was the reason given for this related to the COVID-19 pandemic? Would you/they be happy to continue using the service in this way? • Please explain why Thinking about your/their most recent contact with the Health and Social Care service identified previously, to what extent do you/they agree with the following statements? a) The length of time I waited for the appointment / visit was reasonable b) I was told beforehand what to expect (e.g. what to do or where to go) during the visit / appointment c) During the appointment / visit, I	20-25 minutes

	was given enough information about what to do or where to go d) Staff were compassionate e) Staff took time to listen to me f) Staff adhered to social distancing advice g) Staff used adequate Personal Protective Equipment (PPE) h) I felt safe during the appointment / visit i) My health or social care need was adequately met Have you/they had any health or social care (including tests, investigations, treatment, surgery or routine care) cancelled, postponed or reduced since March 2020? • Prompt: Was it cancelled; postponed, reduced, care was unavailable or not offered? *If so,* Was the reason given for this related to the COVID-19 pandemic? • What impact did this have on you/ them, if any? Have you/they received any private healthcare or social care since March 2020 • Was this due to the COVID-19 pandemic?	
Experiences of Health and Social Care during COVID-19	Do you have any further comments about their experience of Health and Social Care during the COVID-19 pandemic?	5-10 minutes

Information Provision	Do you/they agree with the following statements? 'I feel that I have been well informed about… • Identifying and responding to COVID-19 symptoms • Social distancing • Self-isolation • COVID-19 testing arrangements • COVID-19 contact tracing • Changes to COVID-19 restrictions • Knock-on effects of COVID-19 on other areas of health or social care • The risk of COVID-19 to me as an individual Do you/they agree that information on COVID-19 has been accessible to them? • Please explain Where have you/they accessed information on COVID-19?	10-15 minutes
Conclusion	Do you/they have anything else to add with regards to information from Health and Social Care services during the COVID-19 pandemic? Thank participants for their time and close.	5-10 minutes

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