

Health, Wellbeing and the COVID-19 Pandemic:

Scottish Experiences and Priorities for the Future



ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre



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Insight
People at the centre

A light blue map of Scotland is positioned behind the text, showing the outline of the country.

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Introduction

This paper outlines the lived health and wellbeing experience of a broad range of people living in Scotland during the COVID-19 pandemic, as captured by the People at the Centre Engagement Programme (PATC). It gives insights into how they have viewed health and care services and shares their experiences and stories.

The PATC programme of activity was led by the Health and Social Care Alliance Scotland (the ALLIANCE) in collaboration with delivery partners including Healthcare Improvement Scotland – Community Engagement, in order to rapidly capture insights from people with lived experience to help inform the Mobilisation Recovery Group’s (MRG) work in the re-mobilisation of health and care services. This programme of activity was delivered in alignment and discussion with the Scottish Government led Renew Programme and the Review of Adult Social Care.

Context

A system wide Mobilisation Recovery Group (MRG) was established in June 2020 with a role and remit to:

- Generate system wide input into decisions on resuming and supporting health and social service provision following the COVID-19 pandemic outbreak in Scotland
- Contribute to strategy and policy on how Scottish Government and planning partners best approach and support health and social care reform, as part of the Renew programme, and identify and harness opportunities for transformational change in primary, secondary and community care settings.

A key priority of MRG was to ensure a person centred approach to re-mobilisation across health services in Scotland.

The Cabinet Secretary invited the ALLIANCE, as a member of MRG, to lead engagement work with people in Scotland to ensure there was a wide person centred focus from the outset of remobilisation efforts and, from the perspective of people who access support and services, that the voice of lived experience would be heard.

The PATC Programme was set up to deliver a series of engagement activity, managed by the ALLIANCE, to inform short and longer term reform of the health and care support system, following the COVID-19 pandemic outbreak in Scotland.

The aims of the PATC Programme are to:

- Hear the voices of people across Scotland about what health and care support and services should look like in a post-COVID-19 environment
- Capture learning and feedback on current experiences from people and third sector partners – particularly relating to health inequalities and individuals and communities who have been disproportionately impacted by COVID-19 – to inform the process of remobilising health services
- Better understand the needs of populations and how services can meet public health needs in a sustainable way
- Contribute to informing Scotland’s prevention and early intervention agenda and Public Health priorities
- Design and deliver an inclusive and diverse programme of engagement and communication activity, which ensures people are supported to participate and their voices are heard.

Fundamentals of method and approach

To achieve the aforementioned aims, the ALLIANCE designed a programme of engagement activity that included:

- Facilitating a national conversation on health and care in Scotland
- Developing an ALLIANCE member reference group
- Building public health informed person centred engagement
- Creating a living profile of health inequalities challenges, experiences and solutions
- Capturing community resilience best practice exemplars
- Co-designing a research module for the HIS Community Engagement led Citizens Panel (findings reported separately).

The engagement process was designed with an Equalities and Human Rights Approach as a founding principle and significant work was done to involve people from a diverse range of perspectives, communities, and backgrounds.

Part of this approach included ensuring that there were non-digital engagement options available. Throughout the activities there were opportunities for people to take part using telephone, postal service, or face to face in line with current physical distancing guidelines.

To ensure this diversity of perspective within the programme and increase its reach, the ALLIANCE worked with a range of partners (Appendix 3) and contributors (Appendix 4) from across the health and social care landscape, inviting them to promote the programme's own activities, or to take forward their own.

Further details of the activity undertaken and reach of the programme can be found in Appendix 1.

Across these activities over 1000 people in Scotland shared their views with the People at the Centre programme, resulting in a rich bank of experiential data. In developing this report, the programme took a thematic, qualitative approach to analysing the experiences shared, identifying the common and divergent themes occurring across people's feedback, case studies and wider published literature.

This report does not attempt to reference every piece of evidence submitted, but instead has utilised the wealth of data received to identify a series of themes, which have been informed and supported by a significant proportion of respondents. Where experiences have been noteworthy, but unique or in the extreme, they have been described as such, so that whilst it is clear they do not represent the experience of the majority they can still be considered and learnt from.

A collection of quotes from participants in the People at the Centre programme that particularly informed the themes identified in the report are available in Appendix 5.

The narrative and emergent themes included within this report seek to represent the breadth of experiences shared with the programme, and have formed the basis of the conclusions and recommendations reported. This report therefore offers a snapshot in time of the health and wellbeing experience of people in Scotland during the COVID-19 pandemic and is useful for both understanding what this has been and informing the priorities for remobilisation and the future.

The programme's findings chime with, and are corroborated by, a wealth of other pieces of research which have taken place both in Scotland and internationally, such as the Four Harms Framework¹. Where appropriate these findings have been referenced within the body of the report and further supporting evidence is available in Appendix 6.

Illustrations by www.listen think draw.co.uk

¹Scottish Government (2020) Coronavirus (COVID-19): framework for decision making - assessing the four harms

Opening Statement

By listening to what people have had to say about their experiences, it has been clear just how far reaching the impact of the COVID-19 pandemic has been, touching every aspect of people's lives.

People have told us how the virus and the impacts of the resulting restrictions have disempowered many of them in their ability to access health services and negatively impacted their health and human rights. At the same time, it has also demonstrated how effective people, communities, the third sector and wider healthcare system can be as a collective force.

Peoples' mental health has been impacted. The fear and stress of living through a pandemic has abounded. Reduced access to family, friends, self-care routines and mental health support services have left people feeling isolated and cut off.

Others have experienced a deterioration in their physical health, as health services have prioritised the COVID-19 response, reducing access to the health management and health monitoring supports, which many people rely upon to live well.

There have also, however, been many positive examples given of healthcare services supporting people during this time. Pharmacies and emergency services have been commended in their ability to adapt to changing circumstances and continue to deliver a high quality of care. Examples of effective service delivery during this time can be learned from, scaled up and adapted to local contexts.

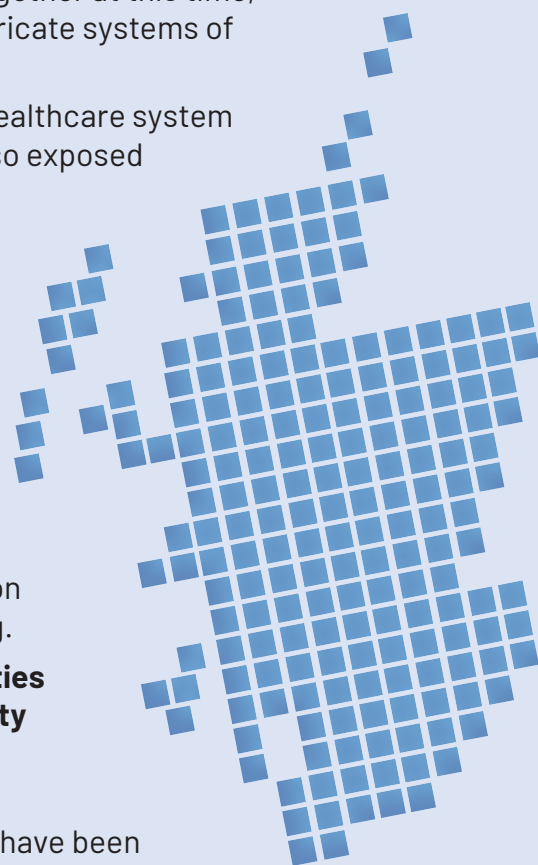
The experiences shared have emphasised the importance of connectedness in our lives and our shared humanity. People and communities have come together at this time, working with the third sector and statutory services to create intricate systems of support and buffer the impact of the pandemic.

Whilst the pandemic has illustrated the collective strength of a healthcare system that works in partnership with people and communities, it has also exposed the breadth of health inequalities that continue to permeate all levels of our society. People living with long term conditions, disabled people, unpaid carers, minority ethnic communities, those who live in Care Homes and many others have shared experiences that describe the disproportionate negative impact on their health, wellbeing and rights evidenced in the wider research.

People have shared how their wellbeing extends far beyond the healthcare services they receive, as does the COVID-19 pandemic. Changes to people's economic circumstances, access to social care support and ability to attend work, education and places of worship all interweave with their sense of wellbeing.

The ALLIANCE would like to thank all the individuals, communities and organisations who contributed to this programme of activity and shared their health and wellbeing experiences during the COVID-19 pandemic.

The following report details the experiences and priorities which have been shared with us by people across Scotland.



Patterns of Experience

Reduced and disrupted access

There has been a lack of access to healthcare services across the board, where the prioritisation of COVID-19 has had an impact on people with non-COVID-19 needs, whose care has been consequently interrupted and delayed and health needs not met. Whilst people have shared their understanding about the unprecedented demand COVID-19 has placed on health services, the impact of this lack of access has been considerable and led to a deterioration of people's physical and mental health.

People reported experiencing a number of disruptions which have impeded their access to healthcare services; health clinics have been paused, outpatient appointments and elective surgery cancelled, face to face appointments reduced or cancelled and waiting times increased.

Many individuals also encountered difficulties when attempting to make appointments or access healthcare services directly, experiencing long waiting times on the telephone, being triaged away from healthcare services and told to "wait and see what happens".

“ They felt like they are inaccessible unless you have COVID. I received messages from GPs advising not to visit the surgery at all, but never received a message saying it was now safe to do so. ”

Digital delivery of services

Where traditional, face to face access to healthcare services has been reduced, this has been supplemented by virtual consultations.

This change has been well received by many, for whom it has brought benefits and greater convenience, such as not requiring people in rural communities to travel long distances for appointments and being able to connect with peer support easily online.

“ Being involved in some of the quickest transformations in health care delivery has been a positive, our infant feeding support have been talking about using Near Me for years, the pandemic forced them to do it and it's been amazing, or so patients are telling us! ”

“ Saves time, travel and fuel. ”

How PATC insights connect to other work

Survey results reveal support for virtual GP appointments, NHS Tayside:

The results of a public survey show that 80% of respondents would be willing to try video or telephone consultation instead of having a routine GP appointment in person. More than 530 people responded to a survey that was shared on NHS Tayside's social media channels. The survey aimed to find out the public's opinion about changes to access to GP services that had taken place during the pandemic.

People have praised better online and telephone access to services, however, not everyone agreed. For some, often those with mental health issues, it was important to see a healthcare professional face to face; it has also been established that not all people can confidently take part in a virtual consultation. Consideration needs to be made for people who are unable or prefer not to access digital technology, who lack the necessary digital skills and/or who may require support from paid/unpaid carers to take part in a virtual appointment; mechanisms need to be put in place which appropriately identify and support these individuals.

We also heard it was important to people to be able to maintain privacy, dignity and confidentiality during a virtual consultation in the home and this should be taken into consideration when carrying out appointments.

Interestingly, there was also a lack of confidence in digital services being able to provide the same level of care and support. It was strongly felt that whilst digital services may be appropriate and effective to use in a variety of circumstances, face to face contact is a basic right which should continue to be available. A significant proportion of people felt that in the context of their health and wellbeing experience, virtual and teleconsultations had been an inadequate replacement to face to face care. For some people the loss of physical examinations resulted in increased anxiety as to whether they had received the correct diagnosis and treatment.

“ I am not confident that health professionals are assessing me properly if they are only speaking to me on the phone. ”

From the experiences shared throughout the programme, there is a clear need for a blended approach to delivering services, which is rooted in choice and flexibility.

“ My daughter had 4 prescriptions of antibiotics issued for a urine infection without a single health professional seeing her! I understand the risk etc but had a GP (who is apparently front line and receiving praise and pay rises through the pandemic for doing what appears to be less work since they are refusing to see most patients) actually examined her and checked urine samples she would have been better with less antibiotics and less time off school unwell! ”

Unhelpful variation in access

People’s experience of accessing healthcare services during the pandemic has been mixed and contradictory.

Vaccinations, particularly the flu jab, have been shared by some as a positive experience, whilst others have had difficulty accessing them. A small number of individuals also shared that cancer screening appointments have continued to take place, though others have been unable to receive breast screening or smear tests.

“ Our kids have had vaccinations and routine appointments over the period with no delay or interference. ”

A range of specialist services have been identified by some as continuing to be delivered effectively, such as the ongoing treatment and support for people with cancer. The picture, however, is contradictory across respondents with experiences of access to rheumatology, orthopaedics and others being shared both positively and negatively.



“ There’s never a good time to discover one has cancer, and the middle of a pandemic is not the best timing – but the support I’ve received in Fife, from a wide range of services, has been exemplary. The local GP’s prompt action, ensuring my hospital admission within two hours of a consultation when she took blood tests, may well have saved my life. ”

The experience regarding access to General Practitioners (GPs) has been particularly varied. Some GPs have continued to be easily available for on-going support and for face to face appointments where necessary, however, this positive experience has not been consistent across participants.

“ GP has been fantastic been readily available has called back same day when it was needed. ”

How PATC insights connect to other work

The response of people from PATC engagement chimes with recent published partner reports. The GPs at the Deep End’s June 2020 report on general practice during COVID-19 identifies how some general practice activities adapted rapidly and universally in response to the COVID-19 pandemic, involving using remote consultations for initial triage and keeping in touch with shielded patients. However, other usual general practice activities such as routine consultations were reduced, some significantly, while others have stopped completely (practice nurse triage).

Experiences relating to accessing, or attempting to access, General Practice throughout the pandemic were the most commonly shared healthcare experience throughout the engagement activity. This emphasises the important role of General Practice as a gateway into the health service and first point of contact, as well as the significance of General Practice to people’s health and wellbeing.

Many people have had positive experiences with General Practice services and shared that they “can’t fault services,” and “have returned phone calls and triaged the same day”, many others have benefited from regular communication and “received weekly phone calls from [my] GP which has been reassuring sometimes twice weekly.”

However, a larger portion of respondents have not been able to access the care that they need and have shared their difficulties in gaining access to their GP.

“ Feel the practice have shut shop since the beginning. ”

This variation in people’s ability to access healthcare, particularly prevalent in the variable access people have experienced in relation to GPs, seems to have resulted from national guidance being interpreted locally. General Practices have, at their own individual pace and aligned with their own local considerations, continued to adapt ways of working instigated by prevailing changing circumstances.

Whilst local variation can in some circumstances be appropriate, any inconsistencies in access, and the reasons for them, must be clearly communicated to those impacted. The topic of communication is discussed further under the heading “Poor communication is a barrier to accessing healthcare”.

People's physical health has deteriorated

People also spoke about the subsequent impact on their health and wellbeing resulting from the disruption to support and services, as well as the disturbance to their lives caused by the restrictions/mitigating measures. For many, this reduced access to services which monitor their health, provide ongoing support and keep them well has resulted in negative implications for their physical wellbeing.

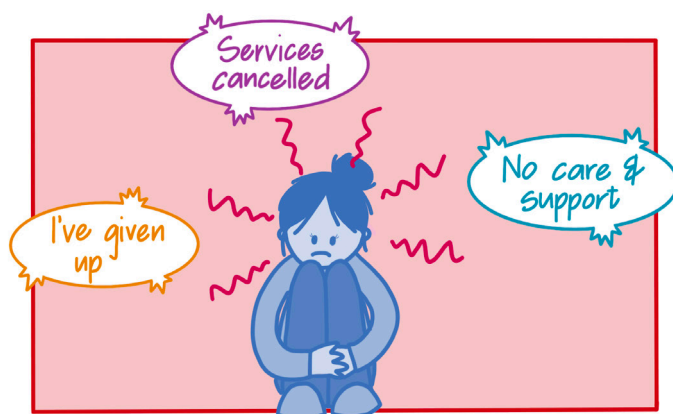
In turn, for some people this lack of on-going support has impacted their wider wellbeing, for example some people have shared that their inability to access ear syringing has left them unable to effectively communicate and socially isolated.

This has particularly been the case for people with long term conditions who have described concerns about the impact on their longer term health and wellbeing, as well as a reduced ability to manage their condition in the short term. People with chronic pain, diabetes and musculoskeletal disorders, as well as other long term conditions, have all shared a lack of access to the basic, ongoing health management they need to stay well.

A perceived lack of consideration for preventative services and routine care was raised multiple times. This was particularly the case for people who relied on community support groups, respite care and ongoing rehabilitation or prehabilitation support.

In some extreme cases, people shared that their inability to access care has not only resulted in their health deteriorating, but has been fatal. While these accounts were rare, they were significant enough to mention within this report and have been shared with Scottish Government directly.

People feel abandoned and frustrated



There has been a strong emotional response from those who have been unable to access services during the pandemic. There has been significant levels of fear and distress amongst people who have had appointments cancelled or their treatment paused.

“ I have been battling with pain for 7 years and to have my appointment cancelled, even though the department is sitting empty (according to the doctor’s secretary) is very disappointing. ”

“ Have been really problematic, resulting in time off due to LTC that usually with the right treatment I can manage. ”

“ I felt as if you’ve got advanced incurable prostate cancer so what else do you expect. ”

“ I have had to attempt to deal with pain and mental stability on my own. ”



“ I have given up trying to access services as I’ve found it so disheartening. ”

This frustration has been compounded by confusion and a lack of clarity surrounding the definition of ‘urgent’ versus ‘non-essential’ care or support during the pandemic. The lack of explanation about decisions around paused services for previously established necessary ‘routine’ or ‘emergency’ care has been described as feeling like “human rights being chipped back.”

This experience echoes concerns raised more widely regarding accountability and transparency in decision-making, scrutiny, the impact of temporary provisions and the safeguarding of human rights during the COVID-19 pandemic under the Coronavirus Act (Scotland) 2020².

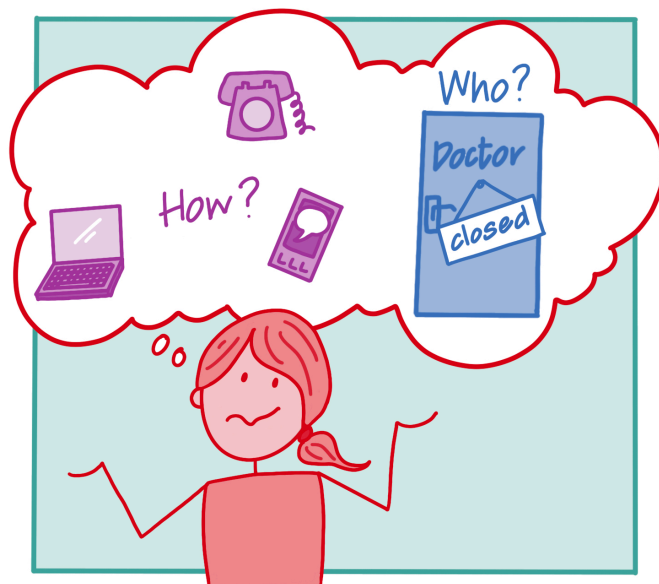
People have also shared feeling dismissed, forgotten and ignored when accessing services with symptoms.

“ The biggest impact notified repeatedly to our Cross Party Group from March 2020 was that no-one could find any emergency help for chronic pain. It was categorised by Government as “non essential” – ”
CPG on Chronic Pain

“ Blood tests, which pre-COVID had been recognised as essential to have regularly, have been paused which has made me feel neglected... ”

Poor communication is a barrier to accessing healthcare

Health literacy concerns



Confusing, limited and interrupted communication was frequently shared by respondents as negatively impacting their health and wellbeing, and ability to access services during this time. These breakdowns in communication have occurred at all levels; between services, between services and those who access them, and at the national public health messaging level.

Information from government agencies has been perceived as erratic. Whilst some individuals shared that they found government guidelines useful, many others found the changing in rules and available services difficult to follow.

A common challenge that people have experienced is a lack of effective communication between individuals and their service providers. Many people have been unable to get in contact with service providers to access support or to make appointments.

²Vicary S, Stone K, McCusker P, et al. (2020) “It’s about how much we can do, and not how little we can get away with”: Coronavirus-related legislative changes for social care in the United Kingdom.

“ It takes a lot for me to ask for help, and when I did it was so difficult to access. I am even getting upset thinking about this and the most annoying thing is no one has got back to me. I presume we are in a queue. I think it would help to have a letter or email even, which acknowledges I have been in touch and says we are dealing with you but it might take time. Otherwise you feel you are in a hopeless situation, you don't matter, your file has been lost, you don't exist, nobody cares - any number of very negative emotions, which aggravate your situation. ”

Others have received unexpected correspondence regarding health and care matters which they have had no other contact regarding. For example, an individual shared that without any notification their partner was discharged into a Care Home that was over one hour's drive away, which they were unable to reach due to a lack of access to transport.

“ It's been really difficult to establish effective communication with my health care providers. I got folic acid supplements added on my prescription without even knowing I was low. There was no communication. ”

Confusion and uncertainty

As well as this, many services have been adapted or redesigned due to the COVID-19 pandemic. Communication to explain changes to care has been lacking, which is why many people have been left unsure and confused about what happens next and when they may resume treatment and regain access to necessary services.

Poor information sharing between redesigned services has also resulted in barriers to people accessing appropriate referrals. For example, one respondent shared being repeatedly redirected between General Practice and Physiotherapy for a chronic pain issue, with neither able to assist.

Another reported being repeatedly referred to a physiotherapist whom they had already received treatment from for long COVID rehabilitation, and who could not provide support for this other aspect of their condition but with no other options of support provided.

“ I reached the top of a waiting list in March. I was supposed to have an appointment since 2019. Now I don't know if I'm still on the waiting list. Am I on or off? ”

The implications and impacts of these adaptations and redesigns have been considered in wider research and other reports, including on staff themselves (Appendix 6).

Inclusive, flexible communication channels

We also heard that information needs to be accessible. A strong theme that emerged is a feeling that the needs of disabled people, people with sensory impairments, or those whose first language is not English have been long overlooked even pre-COVID-19. A priority that was identified across the responses we received was that people accessing health care should be communicated with in an accessible manner including in their preferred language.

In addition to this, people have expressed the importance of services adopting flexibility in frequency of communication and communication methods based on choice and individual preference to maximise access. Unhelpful variation was a feature in the stories people shared with us about communication. Some deaf individuals shared frustration around telephone based triage and being unable to email their GP, while others shared the benefits of being able to do so, indicating the lack of standard communication guidelines.

“ My GP insists on holding telephone consultations and I cannot listen for 10 minutes on the phone as the strain of trying to hear is too much. No matter how many times I have said to the receptionist that I cannot have a telephone consultation, she insists that because I can speak and hear her I can do a telephone consultation. The lack of deaf awareness astounds me! ”

There have, however, been examples of good practice in communication taking place. NHS Inform, for example, are hosting a COVID-19 Communications Toolkit³, which includes a section on alternative formats and new

communication channels. Also, some GPs reported that early on in the pandemic they were concerned that those people they usually had most contact with hadn't been in touch. As a result, mechanisms were put in place to ensure contact was made:

Health Inequalities

“Our care coordinator team set out to make a list of the people we were most concerned about... and picked up the phone. We wanted to check that they were OK, that they had enough food, that they were safe at home, and had enough money. Many of them did not know we were open, or that we could still support them, and they were so happy to receive the calls from people that they knew and trusted.”

Submission from GPs working at “the deep end”

Good practice

Use of Remote Triage, NHS Shetland

“From 23 March all GP Practices in Shetland moved to telephone triage as first point of access, and increased usage of Attend Anywhere. Lerwick Health Centre introduced the “AskmyGP” system, which enables patients to contact the practice 24/7 with queries and to ask for either an email or telephone response. The system currently has a 97% satisfaction rate amongst patients, with very good feedback. It is not the only way to contact a clinician but gives an additional route that patients can use, which is proving particularly popular amongst those for whom an email response is appropriate.

We do acknowledge that the change in access to telephone as first line of access has been difficult for some patients, and there was a reduction in services across our nursing teams e.g. no ear syringing, which was a national decision. Some of the service restrictions will continue owing to the need to have staff available for the COVID 19 vaccination programme, which will be staff dependent.”

³NHS Inform (2020), Coronavirus (COVID-19): Communications toolkit

Health inequalities have been exacerbated and population groups disproportionately impacted

Community Resilience

“The pandemic is reinforcing the underlying health needs and risks being further exasperated. We witness people experiencing adverse health, poverty, isolation, housing, mental health, addiction, fuel poverty, food insecurity, brain injury, learning difficulties, mobility, and literacy issues.”

Recovery Enterprises Scotland

A strong theme that emerged from across the evidence received, which is reinforced by the wider research into the pandemic, is that underlying problems have been exacerbated.



For example, Rowan Alba, who deliver support to people with alcohol acquired brain injury (AABI), highlighted that 95% of people with AABI live alone, 70% have no support network and that they often feel a sense of shame and are embarrassed to ask for help, meaning their needs go unnoticed until they reach crisis.

Another organisation who works with a different population group described the impact:

“ *Everyone just disappeared for a few weeks for our clients. They face barriers to accessing service to begin with. Lockdown and the re-organisation period increased that for them. These people are already living in temporary accommodation, face a language barrier, are often in low paid jobs or temporary roles that didn't get access to furlough and have generally insecure situations and positions to begin with. Most of them 'drop in' regularly in crisis points and now our offices had to shut.* ”

Evidence of this disproportionate impact has been supported by research looking into the short, medium and long-term impact of the pandemic (appendix 6).

People living with long term conditions

As has previously been discussed, people with long term conditions have been particularly impacted by deterioration in their health and wellbeing due to the reduced access to on-going support and healthcare services necessary for them to self manage and live well.

Unpaid carers



Unpaid carers have reported the practical and emotional challenges of providing ongoing care during lockdown. Considerable distress has been described at having to provide even more care for loved ones without access to support and respite.

“ Experience has been difficult, with care responsibility for [my] 80 year old mother and my own disability it’s been trying. ”

This lack of access to day care services and respite has had an adverse impact on their mental health and ability to provide care. The commitment to the Carers (Scotland) Act 2016, and yet lack of planning around this when considering decision-making in the response to the pandemic was raised several times.

Unpaid carers have also shared that they have not been treated as equal partners in care throughout the pandemic. Some have struggled to access appropriate Personal Protective Equipment (PPE), whilst others, to the detriment of the individuals they care for, have been excluded from healthcare appointments and decisions.

“ Assumptions have been made about carers ‘ability and willingness to care’ which goes against the Carers Act. The lack of consultation about the removal and/or reduction of services during lockdown period made carers feel invisible along with a lack of consideration of their ability or willingness to undertake additional caring responsibilities. ”

Community Links Practitioners (CLPs)⁴ share that they have been approached by unpaid carers who have been struggling with providing the carer role during the challenge of lockdown. In these circumstances CLPs were able to make practical arrangements, for instance obtaining walking aids or bathing stools where these made life easier, but also linked unpaid carers to local carers groups for access to peer support.

Good practice

NHS Lothian and the Carer Voices project offered “Check in and chat” telephone support for carers and families of people living with dementia in acute hospitals during the COVID-19 crisis.⁵

Maternity and pregnancy

People have shared that their experience of pregnancy and maternity services during the pandemic has been anxiety provoking and isolating due to the reduction in post-partum follow up services and visitation allowances. Whilst a small number of individuals reported a positive experience of maternity care, mainly in relation to midwives, this was not the case for the majority of participants.

⁴A Community Link Practitioner (CLP) is a generalist social practitioner based within a General Practice. See also: <https://www.alliance-scotland.org.uk/in-the-community/national-link-programme/>

⁵The Health and Social Care Alliance Scotland (2020) Carer Voices and NHS Lothian to offer a carers ‘check in and chat’

People particularly shared their experiences of being unable to be accompanied at medical appointments or have the support of a birth partner. People highlighted the importance of being able to have these support systems present throughout their maternity journey, and the distress they experienced due to them being prohibited.

“ Pregnant women were forgotten about and treated like 2nd class citizens with their rights taken away. ”

Minority ethnic individuals and communities

Wider research has clearly shown that minority ethnic individuals and communities have faced a disproportionate impact of the COVID-19 pandemic on their health, mental health and financial situation (Appendix 6). During this activity, people also shared that many of the structural barriers described in the wider evidence were compounded for people where English was not their first language, or they

come from different cultural backgrounds.

In one extreme example, a respondent shared the stigmatisation they encountered when accessing healthcare services with their child and highlights the importance of cultural and religious sensitivity:

The individual had to go to Accident and Emergency (A&E) because their child had had an accident. This person wears a headscarf, and as they explained their child’s situation the staff asked whether they spoke and understood English in a very condescending way; the individual speaks and understands English well. Their child had memory loss and they did not want to leave them alone in the waiting area, but staff shouted at them “you have to leave”. They were distressed by the situation and did not want to leave their child alone. The treatment and lack of respect they received was a very negative experience for this person.

People also shared the challenges they encountered arranging care and support when English is not their first language. People reported difficulty accessing virtual health appointments when a translator was required as the use of timeslot appointments meant both the individual attending and the translator needed to be available for the entire period. This timeslot could be multiple hours and people found it challenging to coordinate translation services around this level of uncertainty.



Some healthcare information and systems, such as online repeat prescription services, only hosted communication in English and were therefore inaccessible for people who do not read or write English. Another respondent shared that an individual they support had been left unable to receive their care package entitlement as there were no carers available who spoke their preferred language.

It was also shared that larger family units, especially prevalent in South Asian communities, made confidentiality extremely difficult when attending virtual appointments. Reduced access to digital technologies and WiFi was also highlighted as a barrier here.

It was also highlighted that there has been misinformation circulating in some cultural and religious communities regarding the content of the COVID-19 vaccination, with concerns expressed that this could result in reduced uptake for these individuals.

People who live in Care Homes or use Care at Home support

Reponses were collected from a small number of people who live in Care Homes, who use Care at Home support, and their friends and relatives. The experiences shared here highlight just how impacted these two groups have been by the pandemic and associated restrictions, particularly in relation to their ability to stay connected with their loved ones and the outside world.

Poor Wi-Fi connection Deterioration in health No consultation on support change
Regular carers not replaced when off work Lack of access to GP for non COVID problems
Still charged for care not received Staff reports being let down by care home management
Lack of activities, activities stopped Move of floor/room and unable to assist to settle in
Hard to get on the phone with relative because of lack of staff Speech therapy stopped
Lack of response from care homes when concerns raised No weekly updates on relative
No regular testing regime for care workers/not feeling safe because a lot of different carers
No complete reinstatement of care package

“ [My relative] doesn't understand why we are not there and she desperately misses my dad. The Government has done little to make it easier for people with dementia and technology is not the answer for everyone. ”

The responses specifically from people who live in Care Homes highlight the loss of agency they have experienced as a result of the pandemic. People have reported being unable to have visits with family and friends, to access outdoor spaces, or to take part in social activities within their communities, all of which have had a profound, negative impact on their mental health and wellbeing. What comes out particularly strongly from across these responses is the lack of choice people have had in the enactment of the guidelines, and their subsequent feelings of powerlessness.

“ Now I feel like I'm in prison - it's not easy to change. ”

“ Unable to ask for what I want, unable to get out of my room and outside when I want to. ”

“ I have panic attacks and feel lonely. Feel like I'm in prison. ”

Many respondents shared feelings of anger and frustration towards the way in which rules and restrictions were implemented and called for the rights of people who live in Care Homes and use Care at Home support to be recognised and respected. It has been clear from the majority of responses received that the restrictions put in

place were perceived as taking precedence over, and negatively impacting, peoples' wellbeing.

“ Stop this archaic asylum attitude of isolation that many of us fought so hard to abolish decades ago. ”

“ Local authorities carry on breaking human rights and not treating care users as humans.”

Respondents have also cited feeling increasingly isolated, bored and family members have observed their loved ones withdrawing, having lower moods and over sleeping.

“ I think if lockdown goes on for much longer [my relative] will sleep away as she thinks we have abandoned her. ”

“ With nothing to fill the days my relative described it as an asylum with residents walking up and down corridors aimlessly. ”

“ I'm ending my last days like this. It's not easy for everyone. ”

It must also be stated however, that the majority of people who responded praised carers and staff for their kindness and professionalism during these challenging circumstances.

“ What [carers] do in these terrible times needs to be celebrated and the carers should be on much higher wages ”

“ What [the carers do] makes my life worth living ”

People with sensory impairments

As well as the previously discussed lack of Inclusive Communication under the heading “Poor communication is a barrier to accessing healthcare”, lockdown and restrictions have also imposed new barriers for people with sensory impairments. These include difficulties in: lip reading due to face masks; booking appointments online or accessing face to face appointments without a support worker; navigating shops if visually impaired; coping with the impact on public spaces due to changing use of parking spaces; and not receiving a shielding letter on time. Another big issue raised was the difficulties with lip to text translation online.

“ Near Me has also been problematic for people who have deafness, particularly when they are asked to keep repeating things. In one case a man had to depend on his wife as he was deaf- she had to repeat everything. This meant the call took twice as long: unhelpful as the call was about memory. It is also difficult to respond because of pauses and sound distortions. ”



Shielding

This theme of exacerbating existing barriers was also seen for people shielding and their need for additional support. Often, they were the most marginalised and excluded people in society, and the pandemic meant that the support mechanisms they did receive were disrupted.

In areas of multiple deprivation, when lockdown was announced and shielding letters disseminated, many recipients reported feeling overwhelmed by the instructions. There were some instances when the person was unsure what shielding involved, especially if they had not received a Chief Medical Officer (CMO) shielding letter and then subsequently received a shielding letter directly from a GP practice after a consultation.

Confusion abounded regarding who was identified to shield and who wasn't. Some people shared that they believe they should have received a shielding letter but did not. These individuals therefore chose self-imposed isolation to stay safe but were unable to access any available shielding supports.

“I am shielding but I was not on the official list for some reason that no one can explain.”

In some circumstances Community Link Practitioners described having to work closely with GPs and advocate on people's behalf for their names to be added to the local shielding list, in order that they received access to local shielding support.

Digital exclusion

As physical contact has reduced due to the pandemic, and more services and activities are delivered online, digital exclusion has become a prevalent and significant barrier to accessing healthcare for some people in Scotland.

“Tried to get involved in online course but found my technical abilities were lacking and this led to frustration.”

“I can open emails and read them but I don't use Internet because I fear I will do something wrong so getting any help has been difficult and I still don't know what help is available.”

Digital support is not suitable for all and, for example, some people using links worker services expressed that they were uncomfortable using video calls. Some people have felt left out of online peer support sessions because of how uncomfortable digital technology makes them.

Health Inequalities

“Often our patients struggle with the technology, don't have enough data or reliable access to the internet, struggle to articulate their health concerns over the phone, or don't have access to a private space.”

Submission from GPs working at “the deep end”

There are a variety of reasons why an individual may be digitally excluded. Many CLPs described people who were unable to access the internet due to little or no access, affordability or inability to work the technology. This is a well-known challenge throughout General Practice, but GPs suggested that it was more acutely felt in the most deprived areas. Where people did not have access, or were uncomfortable with, video conferencing technology, regular calls have been set up by CLPs to stay in touch with people, or Facebook pages established to allow for continued engagement.

People have also raised the affordability of digital connectivity and the concerns around reliable broadband in rural areas as a potential barrier. While there was general support for digital health and care, some were worried that this could exacerbate inequalities, as not everyone has access to technology or the internet, or the skills to use them.

Inequity of access widening as people seek alternate health supports

People recognise that during the pandemic decisions have had to be made at pace. However, as is discussed further under the heading "Power imbalance", the lack of involvement or consultation about decisions related to their rights to access care has been distressing. This has led to people having to independently seek information online to self-manage their condition, or access private healthcare including dentistry services and physiotherapy. This subsequently raises further concerns around equity in access.

We particularly heard from people who had contracted COVID-19 and were experiencing long COVID symptoms; many of whom described feelings of fear and who felt as though they had been left to research the condition, and possible treatment and support options by themselves.

⁶Realistic Medicine [no date] What realistic medicine is: and what it isn't

“ My husband had a detached retina during COVID and a cataract. Cataract was causing him severe vision loss and as he is my carer needed it removed, however all cataract operations were cancelled as deemed non-essential. He felt he had no other choice but to have this done privately which cost £4000.”

“ My family and I will go private in future I feel for the people who cannot afford that option.”

Reduced person centred care

The need for more accessible and flexible systems and services was raised frequently.

The themes of person centred care, support to self manage health, and the importance of taking a holistic approach to health and wellbeing and risk were described again and again.

People told us how multiple factors affect their health and wellbeing. There was a strong desire that health professionals and services consider the whole person and their life circumstances rather than just focusing on their symptoms or a single condition when they might have multiple conditions, or a range of needs.

People also told us that they want to be listened to and treated with respect, but most importantly treated as an individual rather than a condition. People emphasised how it makes a big difference when they have a good relationship with health and care staff who know what matters to them and their family.

Therefore, lack of continuity of care is a concern and the level of duplication people can face when telling their story can be frustrating - many of these issues have existed long before the pandemic.

“ The process to access a health service can be disjointed, seeing different practitioners and there being no coordination in plan and treatment, people need to be involved in treatment plans, be in control. ”

Power imbalance

People have not been equal partners in their care

As the previous sections of this report have described, a significant concern people have is that they were not sufficiently consulted or involved when their care was postponed and received no support or replacement care options. This included, but was not limited to, dentistry, chronic pain clinics, ear syringing and podiatry services.

People have also not been able to make or share in decisions about their care and how they receive it. Some people feel strongly that having access to face to face appointments is imperative to appropriately diagnose, treat and manage their health, but they have been unable to access these. Others have requested that health services visit them at home as they are shielding, frightened to use public transport or have physical accessibility requirements, but have been denied.

This unequal partnership in care, where people were not involved in the decision making regarding how their care is delivered disempowers individuals and does not recognise their expertise in their own health nor does it adhere to the principles and practice of Realistic Medicine⁶.

“ GP only running phone consultations meant that I still feel unsure about advice to simply ignore a lump I found, despite no physical exam being performed. I don't know what to do, but I feel like I won't get any help if I raise the issue again as they're not doing in person appointments. ”

The challenges people encounter when accessing appropriate health services came up frequently, with some feeling that receptionists and GPs themselves can operate as gatekeepers. This speaks to the power imbalance people are experiencing in their care.

“ GP acts as gatekeeper in rural areas, you can't even get on a waiting list. ”

“ My husband has been experiencing worrying symptoms and can only web chat with a nurse, not even access to online GP they won't even talk to him. ”

How PATC insights connect with others

McCartney et al. 2020 paper "Health inequalities, fundamental causes and power: towards the practice of good theory"⁷ reflects on power as an essential element in reducing health inequalities and offers a framework to identify its most important sources, forms and positions.

In some cases when people's health conditions had worsened there were person centred services such as CLPs who were able to work closely with GPs to make alternative arrangements, for example for socially distanced home visits, as well as liaising with social care about changing circumstances. Lessons can be learned from examples such as this about how partnership working can create flexibility within the healthcare system.

Ayrshire Partnership Staff on improving communication and providing person centred care:

“ One example is mobilising Partnership staff from other teams to help with contacting (door knocking) people on the shielding and vulnerable lists who had not responded to telephone or text communications. ”

More widely than solely the context of COVID-19, some groups of people have described a context within the health service where decisions are made, both at the individual care experience level as well as at the service design level, without any consultation or involvement.

“ A lot of these decisions are made about us without our input or consultation from us and I find that you may have done training or this or that but if you are able bodied you don't live the experience of disabled people... ”

Responsive services

Experiences were also shared of examples of responsive services. People's views regarding their experiences of urgent and emergency services have been overwhelmingly positive. There have been multiple examples of access to emergency services being shared as a positive experience with reference to services such as A&E, ambulatory, surgery and general hospital access.

Most respondents also seemed to agree that pharmacy services worked well for them and exceeded the expectations of the communities they serve. Many people shared that the presence of repeat prescriptions, the access to services close to home, availability, pace of service and the home delivery of prescriptions supported their health and wellbeing at this time.

“ My husband had a laryngectomy - treatment and care magnificent. ”

“ Pharmacy staff to be commended. ”

⁷McCartney, G. Dickie, E. et al(2020)Health inequalities, fundamental causes and power: towards the practice of good theory.
⁸See also: Coutts, P. Bowyer, G. et al(2020)COVID-19 and Communities Listening Project: A Shared Response. Carnegie UK Trust
 Scottish Government (2020), Coronavirus(COVID-19): impact on communities and priorities for recovery - research.



As well as this, some people shared specific examples where services had responded quickly and effectively to support them and their families. People shared instances of specialist nurses arranging regular Zoom and telephone calls for information and support, as well as examples where people continued to receive planned care and the adaptations in delivery, such as virtual consultations, which supported this.

“ I was fortunate that I was able to speak to my GP by telephone and asked for his email and been able to send him my readings without needing an appointment. ”

“ I’ve been seeing my GP on a weekly basis. The contact has been a mixture of face to face and telephone. In terms of what GP practices were facing and how quickly they adapted, I can’t praise them enough. ”

“ Follow up care with daughter in remission, has been kept on track – reassuring. Treatments and follow up for cancer treatment were very intense. Highland managed it very well – bloods and test results on time and follow up appointments with Consultant. ”

Invaluable links

Community Link Practitioners have also been described by some people and professionals as being essential in supporting people during the pandemic.

“ You are a gem and I wouldn’t have been able to get through this time without your support. ”

Links Worker programme participant

How PATC insights connect with others

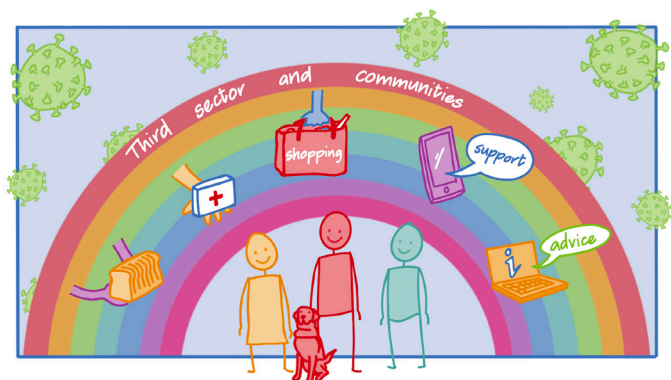
As the Deep End’s most recent report also points out, community link workers have been “invaluable” in contacting vulnerable patients during the pandemic, meeting their needs and making connections with community resources for health.

Health Inequalities

Before COVID-19 this links worker team would meet people mostly face to face in the GP practice, home visits or in the community. Since March, we have not been able to meet people face to face indoors with most appointments taking place over the phone or video call. We have been able to meet some people safely outside adhering to social distancing and COVID-19 restrictions. This can often take the form of a walk or sit in the garden. This provides a few different benefits – fresh air and a health walk, having some face to face interaction with someone and, for the CLW, being able to see a patient’s non-verbal signs and communication.

Buffering the impacts

The role of communities and the third sector



The important role of the third sector and communities in supporting people’s health and wellbeing and providing a buffer against some of the impacts of the pandemic and associated restrictions was frequently referred to. The speed at which the third sector was able to adapt and respond, particularly to the mental health needs and in helping to signpost people to available support were highlighted as positives that have come from this crisis. In this, our findings resonate with other research⁸ and information published about the impact of the pandemic.

“ Carers services had the best response and should assist others, they adapted quickly. ”

“ They are my lifeline to keeping safe and getting help and information. ”

Increasingly, there was also resonance amongst people that the “third sector adapted to deliver services that statutory services were not willing to deliver” – a perception that statutory sector chose to not adapt whereas third sector

filled the ‘gap’, which also relates to the lack of communication and explanation about potential redeployment and resource constraints.

“ I get the feeling professionals are relying on the voluntary groups and I think all the people who are on the NHS Volunteer list are picking up the slack. The public will pick up the slack. I think this is happening virtually all the cases. ”

There was also a strong sense that local, third sector action in many cases preceded government action and provision of guidelines. For example, prior to lockdown, the Pain Association invoked its business continuity plans under the assumption that they could not access the business premises.

The COVID-19 pandemic also saw new needs presenting as a result of both the virus, and action taken to suppress it. People have cited the third sector and their local communities as coming together during this time to mitigate and buffer against the impact of these, and in some cases bridging the gap that has been left by the withdrawal of healthcare services.

Community Resilience

Business continuity planning was in place to enable ongoing operations before and during execution of disaster recovery. Whilst we were certainly not prepared (and who was?) for the scale of disruption that COVID-19 has caused, as an organisation we can take pride in our ability to have changed our service delivery method to virtual within two business days prior to the lockdown.

Pain Association

⁸See also: Social Research (People, Communities and Places), Scottish Government (2020) The impact of Covid-19 on communities, and priorities for recovery: Perspectives of organisations working in communities. Healthcare Improvement Scotland (2020) Health and Social Care Learning System Findings and insights: understanding health and social care responses to COVID-19 and related public health measures.

¹⁰The Health and Social Care Alliance Scotland (no date) Community in Action [online]

Carer:

“ When [my] son was unable to get to relevant groups the neighbours helped. ”

Communities have been empowered and impassioned during this time, with for example, multiple examples of mass volunteer mobilisation taking place. Community resilience has been demonstrated both formally and informally, with some areas developing and implementing complex local support structures, whilst others have created WhatsApp groups with their neighbours in order to stay in touch.

“ Neighbour has walked outside with me every day since I stopped shielding. ”

An increase in community spirit has also been referenced by multiple respondents, with new connections being made between neighbours and the people in local areas. Some people have shared how these connections have been instigated and nurtured by regular, group activities such as the Clap for Carers, or organising a daily, socially distanced street dancing session to keep spirits and fitness up during lockdown.

Community Resilience

“Our community approach is far more than providing food; its connecting on a human level, raising self-esteem and worth. Our engagement is always about treating people with respect, who have rights, strengths and aspirations. Our team is viewed as a trusted provider of assistance, returning weekly and carrying out any actions agreed.”

Recovery Enterprises Scotland

“ Clapping for NHS was a nice way to have community come together. ”

The third sector and communities have addressed newly presenting need during the pandemic through provision of activities such as: peer support, local food provision, delivery of prescriptions, addiction support and others (further examples are available in Appendix 7). Multiple reports⁹ highlight community level organisations’ quick response and adaptability when facing the pandemic.

Health Inequalities

P is missing her regular in person interactions with her peers and in particular her Bookclub for the Blind which used to meet monthly. Telephone befriending and a local walking group have both been offered to Patient P as alternatives to try whilst her usual group is not running.

Over 60 case study examples of the third sector’s rapid and flexible response to COVID-19 have also been captured in the ALLIANCE’s Community in Action series¹⁰.

People are assets in their communities

It is important to note as well, that during this time people have been assets in their communities and to the healthcare system. Many respondents have found new self management strategies and ways of keeping themselves well – those most often cited included going for a walk, baking, knitting, spending time in green spaces, and staying connected with others.

People have also drawn upon friendships, neighbours and networks for support in creative and innovative ways, identifying what is working

¹⁰Healthcare Improvement Scotland (2020), Health and Social Care Learning System Findings and insights: understanding health and social care responses to COVID-19 and related public health measures.

well for them and their families, and accessing a different range of online resources to help them manage these unusual circumstances.

“ I started doing arts and crafts in my kitchen and posted pictures of the results on Facebook, made me feel good about myself. ”

“ I learned how to do mindfulness and now do it every day, helps keep me calm. ”

People and communities have also actively supported the response to the COVID-19 pandemic by not only complying with guidance themselves, but by creating the conditions locally by which people could reduce physical contact and keep themselves safe whilst maintaining access to necessary social contact and healthcare support.

“ Tried to maintain level of cleanliness and safe distancing at all time. ”

“ Community groups have been better than official services. ”

Working better together

It has also been shared that throughout the pandemic, organisations, individuals and communities have worked in partnership to provide innovative, adaptable and effective services. Trusting relationships are a key aspect of this, within and between different types of organisations, and allow for developing new

services, increasing staff confidence,¹¹ better understanding and seeing beyond competing for funds¹².

Community Resilience

There was evidence of greater partnership working and eagerness to collaborate to problem solve and share experiences. Responsiveness of external agencies and others to requests for help, knowledge and advice was excellent.

Marie Curie

The Community Resilience Best Practice case studies identified six aspects of successful partnership working (see Appendix 8 for the detail of these) which have been effectively demonstrated by organisations, communities and individuals during this time and can be learned from:

- Coming together to form new entities
- Making use of existing infrastructures
- Working towards shared vision
- Virtual communication underpinning successful partnership working
- Third sector acting as a link between community and councils
- Future collaborative working.

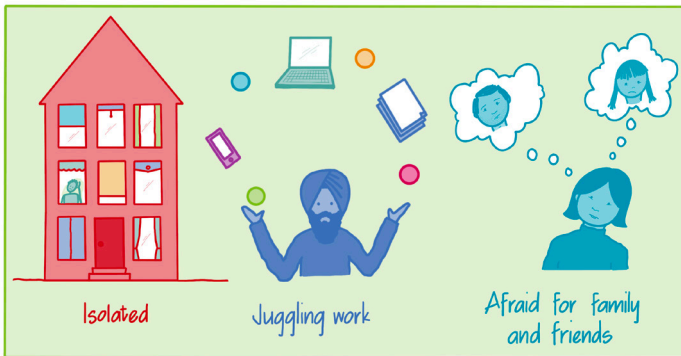


¹²Coutts P, Bowyer G, R et al (2020). COVID-19 and Communities Listening Project: A Shared Response.

Evidence of the Wider Impact

It is clear that the health and wellbeing impact of the COVID-19 pandemic extends far beyond people's experiences of healthcare services.

Mental health impact



The response from PATC engagement demonstrates that there has been a significant, negative mental health impact on the people of Scotland during the pandemic. For many people the stress, fear and worry of living through a pandemic has caused a considerable strain on their mental health, exacerbated by the reduced availability of mental health services (Appendix 6).

This is particularly true for those people with existing mental health needs living in areas of multiple deprivation, where the pandemic is creating additional anxiety and uncertainty, coupled with increased difficulties in accessing support. Community Links Practitioners also identified that there are many people living in deprived areas who have been struggling with their mental health for a while, but have not yet managed to access support, and others who are experiencing anxiety for the first time as a result of the pandemic.

Health Inequalities

“Mental health is usually a significant part of our clinical workload, but we have seen a further significant increase in the volume of mental-health related presentations (those with existing mental health issues worsening, and many developing new mental health difficulties).

Submission from GPs working at “the Deep End”

There is also evidence that disabled people are more likely than non-disabled people to report feeling more anxious, worried about becoming seriously ill with COVID-19 and their own mental health or feeling lonely¹³. Other groups such as socio-economically disadvantaged people, children and young people, older people and women are experiencing a high impact on current and future mental health and/or increased risks of loneliness¹⁴.

The isolation, loneliness and anxiety people have felt, and are feeling, cannot be overstressed. For many the emotional toll of living during this time has been compounded significantly by an inability to see friends, family and take part in their usual self-care routines.

“ *It’s been extremely negative on my mental health and well-being to never leave the house. Particularly that I cannot visit family.* ”

“ *The fear and isolation has been devastating.* ”

¹³Social Research (People, Communities and Places), Scottish Government (2020). The Impact of Covid-19 on Wellbeing in Scotland.

¹⁴Housing and Social Justice Directorate, Scottish Government (2020). Coronavirus (COVID-19): impact on equality (research). Scottish Government (2020).

Scobie G, Whitehead R. (2020) What are the impacts of past infectious disease outbreaks on non-communicable health outcomes? Public Health Scotland.

“ I live alone and have no immediate family so loneliness has been a real challenge and continues to be so. I miss being able to visit friends, locally or further afield, or have them visit me. ”

The fear associated with contracting the virus and, as a consequence of this, physical contact, accessing communal areas and public spaces is causing some individuals to withdraw from society into self-imposed isolation; often with significant detriment to their mental health. Due to this some CLPs have expressed concern that those they work with will likely struggle to get back “out and about” quite as easily as they did previously.

“ Basically, just not going out... just stay at home in my bed. The house I’m in at the moment isn’t suitable for me now, it has up and downstairs and I’ve fallen down the stairs about 10 times in lockdown so now I just stay upstairs where the toilet is so that I’m safer. I don’t really use my living room now and I only go downstairs to eat and then come straight back up. ”

Additionally, as a consequence of the pandemic, many people are also experiencing recent bereavement related to close members of their family who had contracted COVID-19. This has, unsurprisingly, had significant emotional

implications for the individuals involved and has also been compounded in circumstances where family members were unable to be with their loved ones at the end of their life.

Family and friends of people who live in Care Homes have been particularly affected by this lack of contact with their loved ones. They have reported feeling worried and anxious regarding the wellbeing on their family members. There has been particular distress when people have died in a Care Home setting without the presence of their family or friends, with one extreme example being shared:

“ I was completely bewildered and was sobbing uncontrollably in distress. She raced me towards the entrance and sat me down on the bench outside the door. She wanted to make me tea but I didn’t want tea, all I wanted was to see my husband. She then told me that he was dead. I was almost hysterical with crying and in a really distressed state. She said that I could not see him as rules, regulations and protocol demanded that no visitor was allowed inside the home. ”

This period of time has also been considerably stressful for frontline workers, particularly those involved in the delivery of health and social care support. Evidence on the impact of past infectious disease outbreaks on non-communicable health outcomes shows that the greatest mental health impact is generally reported among healthcare workers¹⁵.

¹⁵Scobie G, Whitehead R. (2020) What are the impacts of past infectious disease outbreaks on non-communicable health outcomes?. Public Health Scotland.

“ Being redeployed to Covid-19 services, no one checked to see how I was coping with new job. ”

“ Senior roles relating to the response have been stressful and depressing. ”

It must also be acknowledged, however, that for a small minority the lock down period has eased stress and positively impacted individuals.

“ Less stress due to not having to travel for work. ”

Some young adults reported that their mental health has improved during the crisis. School closures during the lockdown period have positively impacted some young people’s mental health as they “don’t have to worry about the bullies.” Other members of young adult support groups described the “relief” that they have that others are now sharing their feelings of anxiety, which is giving them a sense of “fitting in and feeling more normal.

Delivery of, and access to, mental health services

As with wider healthcare provision, experience of mental health services has been mixed, though of those who responded, negative experiences outweighed the positive. At this time of increased need for mental health support, a prominent theme which has emerged is

its reduction in availability. This inability to access appropriate mental health support, coupled with the wider stresses of the pandemic, has resulted in people reaching crisis point.

One individual described the deterioration of their mental health; they tried to take their own life several times while they were shielding. Although they were taken to hospital, usually by the police, they were discharged almost immediately and sent home, without support, to be alone in their house. Community health and social care services were informed, but often did not respond by calling. The eventual response was to make a referral to social work and for the CPN to phone to check up on how the person was doing.

“ Nothing has worked well. My daughter had no support for 6 months. She was in services and had weekly appointments until COVID. She is now at crisis. ”

“ GP taking time to listen and offer support. ”

“ Overall lack of access. ”

“ Excellent mental health support for son. ”

One aspect that came out clearly is the role third sector organisations have played

in supporting people’s mental health. COPE, Pillar Kincardine, Breathing Space, SilverCloud and Carers Trust Scotland are just a few of the third sector organisations explicitly mentioned by respondents as working well for them and supporting their mental health.

“ COPE Scotland cares about people no matter who calls them you get a service. ”

Digital mental health delivery

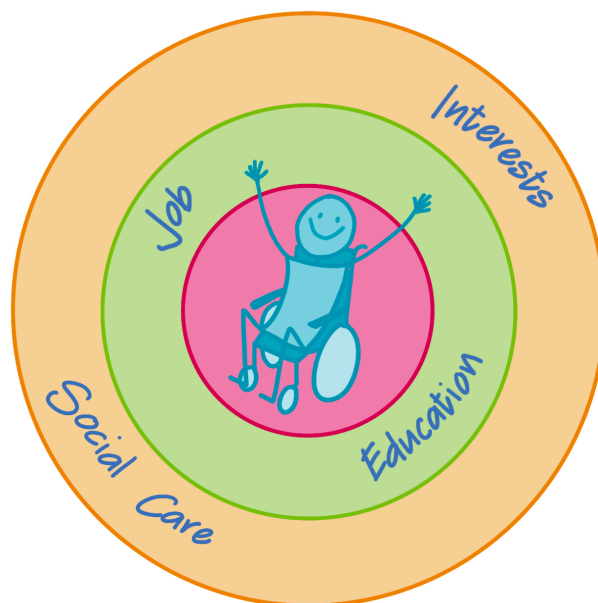
Throughout the pandemic, many mental health services have been moved online, or over the phone. However, the majority of participants shared that they found the digital delivery of mental health services to be inappropriate and an ineffective model of delivering support.

Many people are uncomfortable using online and telephone services for this type of support, and are, as a result, going without mental health support. People shared that the inability to see and read body language was a barrier for them using services this way, and also the lack of access to a private and confidential space.

“ I didn’t find talking on the telephone, to someone I’ve never met, either helpful or comforting. ”

“ Not a suitable platform for sharing traumatic themes. ”

Wider determinants of health and public health impacts



Sense of wellbeing

With the significant impact that the COVID-19 pandemic and associated restrictions have had on the way in which we live our lives, its wellbeing impact extends far beyond the delivery of healthcare services.

For example, some people have shared that their wellbeing has been negatively impacted by the lack of access to public services including pools and libraries. Whilst others miss self-care habits such as attending the gym or going to the hairdresser.

“ Devastated that library closed as reading keeps me sane. ”

“ Not being able to swim daily has had an incredibly detrimental effect on both my physical and mental wellbeing. ”

Disabled people and people with reduced mobility also reported facing significant barriers when accessing public spaces. In many cases physical accessibility had been reduced. For example, multiple people were unable to use disabled parking spaces, as they were being used instead for queuing systems. Stigmatisation was also prevalent, with people being challenged and accused of ignoring guidance for driving to local areas to exercise, or for resting on benches.

“ I found that I couldn't go to the shops. After having to stand in line to get in, by the time I got to the front I was too sore to actually go into the shop. A lot of disabled spaces were cordoned off to make walkways with social distancing. Disabled and elderly were completely forgotten about.”

How PATC insights connect with others

Wider research also found that the wellbeing impact has been unequally distributed among the population: groups who were vulnerable before the pandemic have either increased vulnerability or were impacted more significantly. For example, people who already felt low happiness before the COVID-19 pandemic are more likely to report that they tend to feel worse than before because of it.¹⁶

Financial and economic impact

The impact of the pandemic has been truly cross sectoral and new and enduring financial issues have been a significant feature in the evidence received. In some cases, anxiety and depression was caused by job insecurity

and worries about the financial implications of potential job loss for themselves and their families. People who had been furloughed were unsure how long this scheme would go on and whether their income would be protected to allow them to continue to follow the shielding guidance.

“ Poverty might kill more people than COVID.”

“ My partner was made redundant and is unemployed, my job is now at risk of redundancy. I can't access support from friends and family, or professionals. I feel I have no control. Financially things are pretty tight, [I'm] worried about heating costs during the winter. It's put us in real hardship. My partner has experienced poor mental health for the first time this year.”

People's work situation, workplace and working habits have also changed dramatically as a result of the pandemic. For example, some employers have not allowed people to work from home causing fear and anxiety for their employees.

For others who have been able to work from home, the experience has been mixed. Some have been able to support their wellbeing through healthy eating and a lack of commute, whilst others have struggled to balance arrangements for working from home with factors like caring for young children and crowded home environments.

¹⁶Social Research (People, Communities and Places), Scottish Government (2020) The Impact of Covid-19 on Wellbeing in Scotland.

How PATC insights connect with others

Wider evidence has also shown that the financial impact of COVID-19 varies according to an individual's situation and characteristics. For example, men are more likely than women to have been furloughed, but women are more likely to be working more hours than before; young people are more likely than older people to have a lower income; households with children are more likely to have had difficulties paying bills or their rent than those without; and disabled people are more likely than non-disabled ones to have difficulties paying bills and collecting pensions or social security.¹⁷ Evidence also suggests that disabled people will be affected by shutdown in some sectors, due to their higher share of employment in those, reducing labour market outcomes. This is also true for people of minority ethnicities, who feel the economic impact of this crisis harder¹⁸.

Generally, people in the most deprived areas were most likely to have lost their job or been made redundant, to have applied for universal credit or to have received support from care workers or a charity versus those in less deprived areas. It is important to consider the disproportionate impact of COVID-19 among these more vulnerable groups.¹⁹

“ Working from home with a normal workload whilst caring for an autistic child has been too much. ”

“ Working from home has made it easier to eat healthier. ”

CLPs have also been supporting people to undertake employment appeals throughout the pandemic but there have been cases where appeals have been put on hold at great stress and mental health implications to the individual involved.

Personal Independence Payment (PIP) and other social security assessments have also been completed over the phone, leaving some people unable to carry out the assessments and missing out on benefits to which they were entitled. This has been particularly true for people with mental health difficulties for whom speaking on the phone can make it particularly difficult to engage fully in remote processes.

Access to social support has been interrupted

In some cases, the regular social support provided by social care providers available to people pre-pandemic was paused during the lockdown period. This meant that some people were unable to engage with the things that kept them well.

Formal social care support became difficult to access with, for example, CLPs experiencing long waits to contact social work. The majority of people who access Care at Home support also reported having their care packages cut in some way with very little or no notice to these changes. Where day care has been reduced or removed it has proved to be difficult to get any service reinstated and few alternative options were presented.

“ As a disabled person (sight-impaired, chronic pain) I have lost all outside support with my day-to-day housework assistance and help with shopping. ”

¹⁷Social Research (People, Communities and Places), Scottish Government (2020) The Impact of Covid-19 on Wellbeing in Scotland.

¹⁸Housing and Social Justice Directorate, Scottish Government (2020) Coronavirus (COVID-19): impact on equality (research).

¹⁹Social Research (People, Communities and Places), Scottish Government (2020) The Impact of Covid-19 on Wellbeing in Scotland.



Beyond Survival: This is What Matters to People

As part of the programme of engagement, people were asked to explore their priorities for the future, and help to inform decision making for remobilisation, recovery and renewal. This section outlines the themes that emerged in people's responses and outlines eight interconnected recommendations that emerged from our analysis.

People shared a range of responses when asked "What matters to you?"

People were asked specifically about: online booking; face to face access; support and advice to manage their own condition; services close to home; general access; waiting times; involvement of families and carers; and 24 hour treatment centres.

All were felt to be important, highlighting the multifaceted nature of healthcare support, with general access to services and access to face to face services being the two highest ranked factors respectively.

The thread that carried most strongly through these responses was the importance of choice and flexibility. People felt strongly that they should be able to access these services if they needed them. However, it was also felt strongly that if people needed another type of support that this should also be available to them.

Issues of digital exclusion, ability to travel, rural versus urban areas, were all raised as being important contextual considerations when exploring what services should be available and how they should be delivered.

Online booking -

“ Fantastic for inclusive communication for the deaf. ”

“ [I] prefer human contact, at the moment I have the ability to do it online but not if I can't afford to pay my phone bill. ”

“ For long term conditions there should be at least a phone number where you could get immediate advice. ”

“ I think it is unfair for people to have to travel pan Lanarkshire because services are being centralised at certain hospitals. ”



1) Holistic, person centred care as the foundation of healthcare services

Most people shared that they don't want a choice between access and continuity, they want both: a timely appointment either face to face or digitally, depending on their preference and with a doctor they know and trust.

People really value the relationship they have with health professionals. They need and want continuity, to be listened to and would benefit most from an ongoing relationship with a single GP or team; this is especially true for people with a range of needs.

Flexible, person centred healthcare services, which recognise the holistic nature of individuals are therefore fundamental to meeting people's needs.

“ Greater personalisation of care driven by the patient's expressed need. ”

How PATC insights connect with others

The Healthcare Quality Strategy for NHS Scotland describes person centred care as:

“Mutually beneficial partnerships between patients, their families and those delivering healthcare services which respect individual needs and values and which demonstrate compassion, continuity, clear communication and shared decision making.”

2) People as empowered partners in decision making

In order for person centred care to become embedded, people with lived experience must be equal partners in decision making across the healthcare system; from service design, to the everyday delivery of their care.

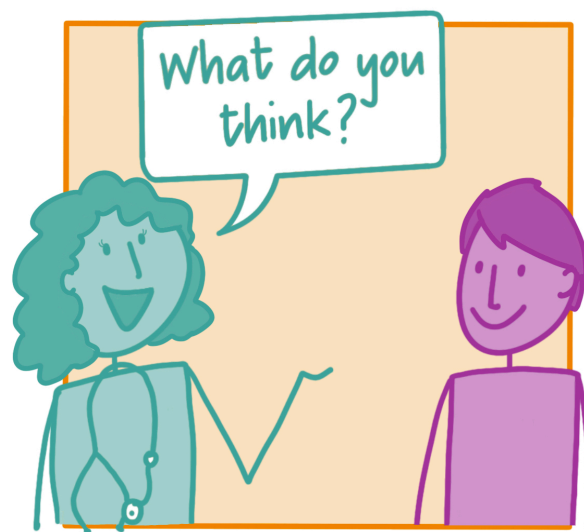
“ Involve people in designing services from the start - this is human system and top down is not best. We need to work together with professionals to look at what kind of services we want, need and can afford. ”

Being involved in the decision making process and treated as an expert in their own life circumstances and care, and the care of loved ones, has been shared as being of the utmost importance to people.

To deliver this, the principles of co-design and co-production must be embedded within the healthcare system, as well as a House of Care Approach²⁰ to person centred care and support planning.

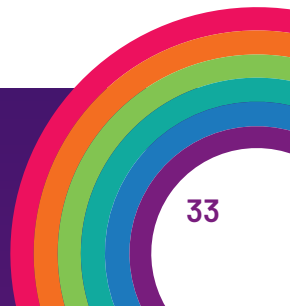
“ Choice of when, with who and how to be seen. ”

As services remobilise, people need to be involved in the process of establishing and identifying their own acceptable risk levels; balancing risk associated with the pandemic with people's own long term health. Engaging people as part of the ongoing solution is a key strategy in the response to a pandemic advocated by the World Health Organisation.²¹



²⁰The Health and Social Care Alliance (no date) Scotland's House of Care.

²¹World Health Organisation (2020) Pandemic fatigue Reinvigorating the public to prevent COVID-19.



3) Resourcing thriving, vibrant, asset-based communities

The pandemic has highlighted a plethora of community-focused action which demonstrates the many examples of individual and community assets that exist across Scotland.

The learning from this community response highlights the value and contribution of asset based approaches; a way of working which values and supports the skills, strengths and successes of individuals and communities. The resilience people have described and shown during the pandemic demonstrates the importance of achieving a balance between meeting people's needs and nurturing their strengths and resources. For communities to continue to develop as empowered components of the healthcare system we must move away from the paternalistic medical model.

How PATC insights connect with others

The role of communities in healthcare systems has also been explored in Cormac Russell's "We don't have a health problem, we have a village problem"²²

"Community is the smallest unit of health, not isolated individuals".

Adequate resourcing is required to nurture these vibrant communities to grow organically and sustainably. Access to appropriate public spaces²³ and services, as well as economic investment and development in local areas all contribute to creating the conditions for communities and their individual members to flourish.

Many people also highlighted the valuable role of the third sector in local communities, but also the impact of short-term funding on the sustainability of services. In particular people shared the importance of retaining positive outcomes of the

pandemic response which has included digital innovation, community spirit and partnership working.

People have valued the role of the third sector in supporting them during this time and investment to ensure their long term ability to deliver this has come out as a priority.

Community Resilience

We seek resources reflective of the demands and impact; and enabling us planning for ongoing support, opposed to uncertainty of limited funding. We have an understanding of local needs where other services are unable to connect.

Recovery Enterprises Scotland



4) Access to equitable and consistent care

People also want equal access to services no matter where they live or what protected characteristic they have. People described 'postcode lotteries' affecting standards of care and level of communication. Many people shared the feeling that if you were already

²²Cormac Russell, (2020) We Don't Have a Health Problem, We Have a Village Problem.

²³Public Health Scotland (no date) The Place Standard Toolkit.

in the system receiving care pre-pandemic, there is more likelihood of better access, care and support during the current situation than otherwise. The data has made clear that there is variation in the type of service provision, quality of care and access across Scotland, often even within geographical areas.

While it is appropriate and expected that practice has been adapted to suit local contexts and the fluctuating prevalence of COVID-19 infection in the community, more must be done to ensure that there is a standard consistency of care and equitable access to services across Scotland and for all groups of the population.

5) Clear, inclusive communication

Investing in clear, accessible information about the support that is still available and how people can access it is required. People have not been aware of their right to access available care due to a lack of clear and consistent communication, and this has reduced trust in quality of care and rights-based care. To address this, as services remobilise and deal with the backlog of care, individuals need informed expectations of care and waiting times.

“ My hospital appointment was cancelled by letter and reassurance was given by telephone that my appointment would be rearranged. ”

6) Digital, but not as default

For many people the innovative and accelerated implementation of virtual services improved access, made it quicker, and

supported more choices for the individual. People have welcomed the use of this technology and its wider implementation and use should continue.

However, it is important that digital services are offered as a supplementary channel to access services, and that other routes such as face to face remain available. As has been shared, face to face contact is important to people, particularly for groups who experience barriers to digital technologies and those who access mental health support.

It is clear that ‘one does not all fit all’ and services should offer a blended ‘Digital Choice’ approach; people want to feel empowered and have a choice in how they wish to access health.

Codesigning digital services with users might be a route to ensure online services are adapted to the target population: one example is a project based in the Isle of Skye which aimed to codesign the use of the NHS Near Me platform, in a wider goal of reforming Outpatients Appointments. The project learnt from users to adapt the platform to their needs.²⁴

Another example is Children’s Hospices Across Scotland’s (CHAS) experience of implementing a telehospice programme during February and March 2020 in response to the pandemic²⁵. The pandemic accelerated a pre-existing plan which consisted of: establishing telehospice governance mechanisms, developing key outcome measures and restructuring personal and team. Despite technology challenges, the virtual hospice allowed for the provision of kindness calls, virtual appointments or bereavement support. The case study highlights the importance of equity and parity of service delivery, continuous measuring of key outcomes and linking up with support services²⁶.

²⁴Beattie M, Morrison C. et al. (2020) Near Me at Home: codesigning the use of video consultations for outpatient appointments in patients’ homes.

²⁵Ellis K, Lindley L C. (2020) A Virtual Children’s Hospice in Response to COVID-19: The Scottish Experience.

²⁶This ihub report also looks at Technology Enabled Care and the importance of addressing digital exclusion and building the capacity of health and social care staff to provide digital services: Healthcare Improvement Scotland(2020), Health and Social Care Learning System Findings and insights: understanding health and social care responses to COVID-19 and related public health measures.

7) Prioritising mental health recovery

As we begin to look beyond the COVID-19 pandemic, people's mental health recovery must be a priority for healthcare services. As has previously been shared, this is an area where a significant, negative impact has been felt.

A trauma informed approach must be taken to address and support the significant negative experience people have encountered as a result of this pandemic. People must be empowered to comfortably reintegrate into their communities and society as a whole, and, for some, trust and relationships needs to be rebuilt with statutory services.

Key workers in health and social care are also a significant group who must receive appropriate mental health support, after their experiences fighting COVID-19 on the front lines.

How PATC insights connect with others

The Royal Pharmaceutical Society and Pharmacist Support's annual survey on pharmacists' mental health and wellbeing²⁷ demonstrated the impact of COVID-19 and workplace pressures on pharmacists:

- Over half (54%) of pharmacists believed that COVID-19 had impacted their mental health and wellbeing to a partial extent
- nearly a third (31%) said it had to a significant extent.

8) Investment in the NHS

People have shared that they really value the NHS, the people who deliver it and the provision of healthcare, but that it requires increased investment to be able to deliver the level of care and outcomes to which they aspire.

“ I'd like to pay tribute to our amazing health care workers from the cleaners to the secretaries, to the physios and doctors. They have been incredible. ”

Mental health and prevention and early intervention services were both raised as areas for increased investment, clearly indicating people's desire to have access to a healthcare system which supports them to live well.

“ Investment in direct access mental health service and social care. ”

“ In order to stay well certain things are necessary. Good diagnosis, early correction of problems, support if required. ”



²⁷Royal Pharmaceutical Society (no date) Workforce Wellbeing: Mental Health and Wellbeing Survey.

Closing Statement

Every person in Scotland has, in ways that are unique to their circumstance, been affected by the COVID-19 pandemic. In response to the virus, healthcare services and systems were rapidly redesigned, whilst at the same time, the implementation of new restrictions and guidance significantly altered people's daily lives.

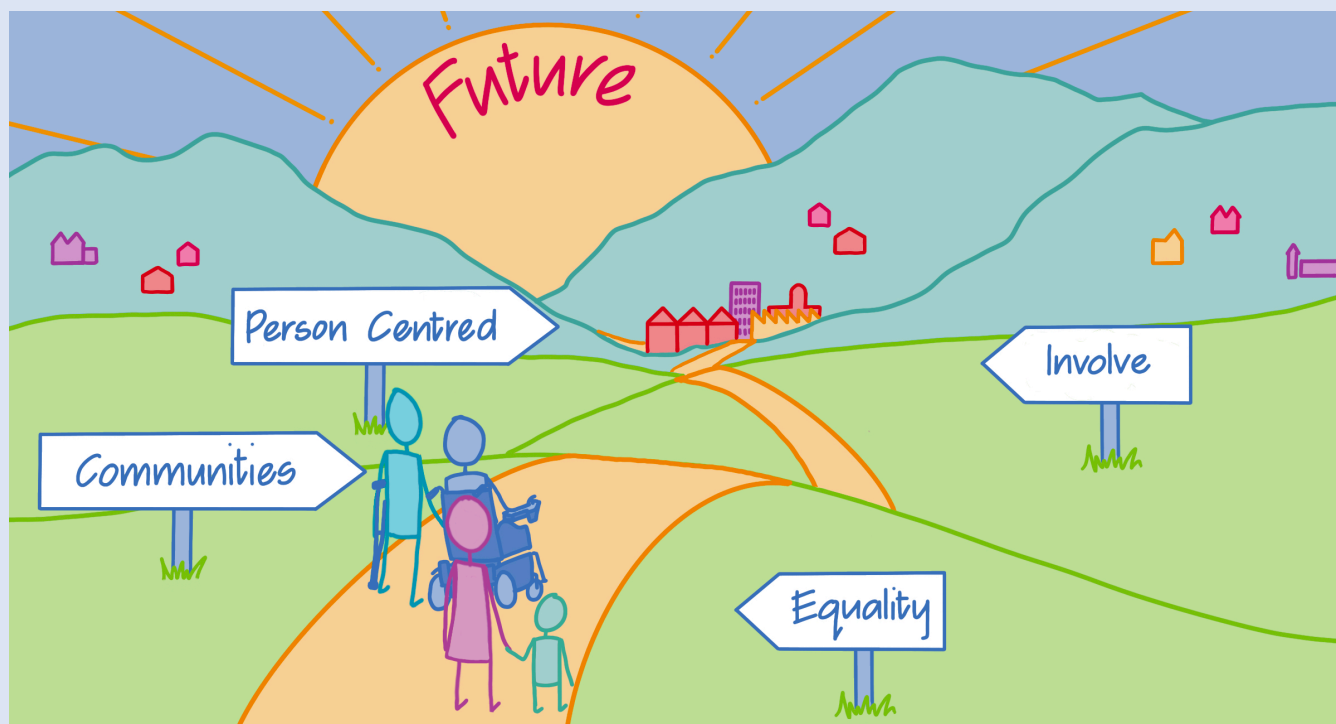
Through a process of enquiry and engagement, the People at the Centre (PATC) programme has heard how the impact on people's health and wellbeing has been significant. Many of which echo those from other pieces of research which have been taken forward during this time, both in Scotland and internationally (Appendix 6).

This has been a challenging and unprecedented time for healthcare services, where they have sought to balance the need to fight the COVID-19 pandemic with continuing to ensure the availability of much needed wider services; all at a time of increased constraints on capacity and resources. People have recognised and commended the healthcare system for these efforts.

However, the speed of redesign and the limitations imposed on access have negatively impacted the health and wellbeing of people in Scotland, increasing feelings of isolation, abandonment and deteriorating physical and mental health.

This report has captured peoples' experiences of this pandemic during a moment in time, what their priorities have been and what matters to them. As healthcare services remobilise, lessons can be learnt from these experiences about what people fundamentally need to be in place to live well.

In the coming months and years, the remobilisation of healthcare services provides a unique opportunity to rebuild, redesign and renew the healthcare system in Scotland. People should continue to be involved as active and equal partners in every step of this process, informing and contributing to the development of a healthcare service with people at its centre.



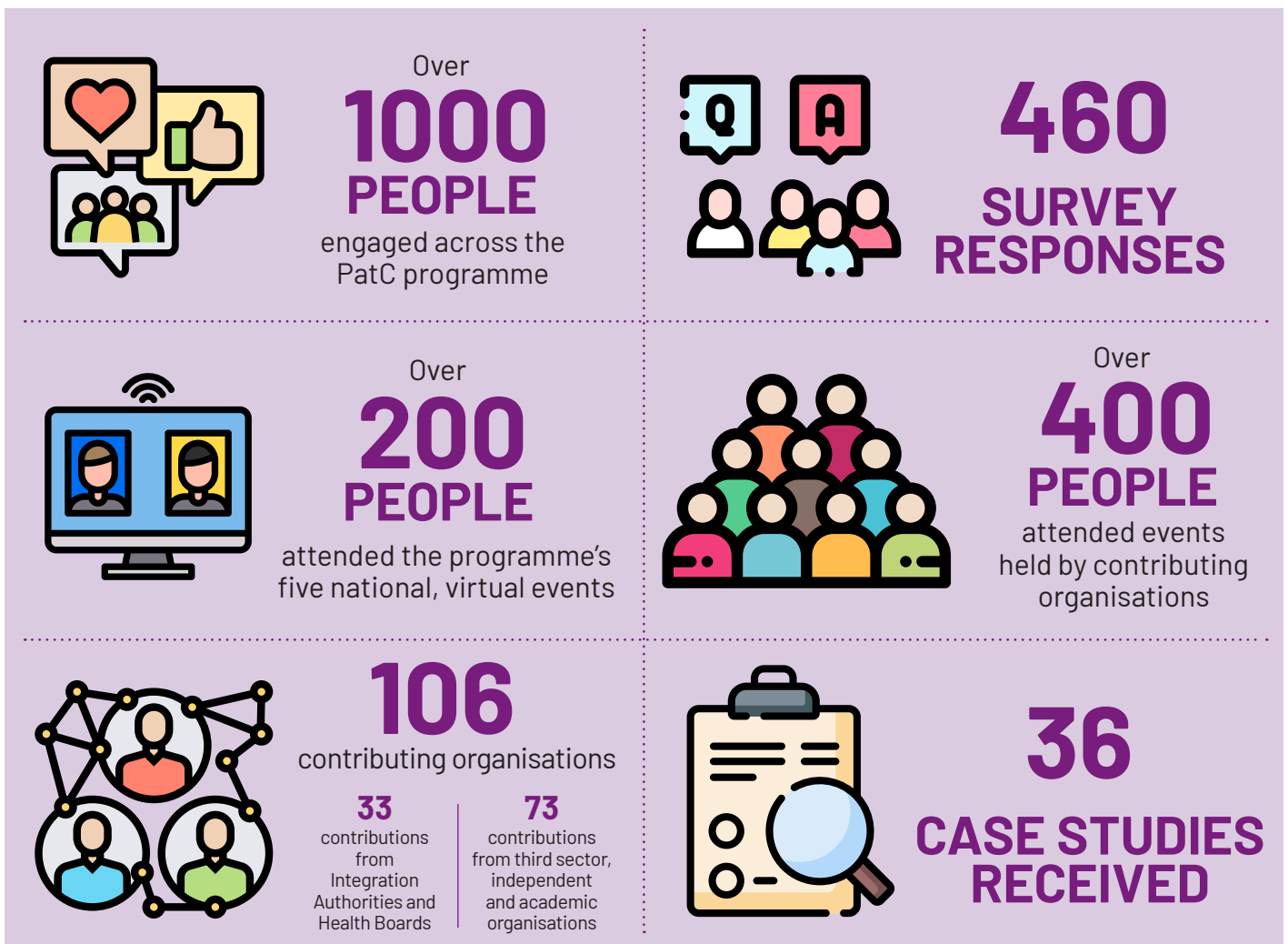
Appendix 1: Methodology – data collection

The People at the Centre Programme was set up to deliver a series of engagement activity to inform short and longer term reform of the health and care support system, following the COVID-19 pandemic outbreak in Scotland.

The programme aimed to design and deliver an inclusive and diverse programme of engagement and communication activity which ensured people were supported to participate and have their voice heard.

To do this the ALLIANCE developed a mixed method project underpinned by a human rights and equalities impact assessment which provided several avenues for individuals and organisations to submit their views. The ALLIANCE worked flexibly with people and partners throughout the programme to facilitate and support people to contribute.

Key Numbers



A national conversation with the people of Scotland

As part of this programme the ALLIANCE, in partnership with Healthcare Improvement Scotland – Community Engagement, held a national conversation with the people of Scotland. Seeking to engage all parts of Scottish society in a dialogue about the future of health and care in Scotland, to discover what mattered to them and to co-produce practical proposals for creating services fit for a ‘New Reality’ post-pandemic.

To guide this conversation the ALLIANCE and Health Improvement Scotland-Community Engagement (HIS-Community Engagement) developed a set of questions examining three key areas:

- People’s experience of the pandemic
- What matters to you?
- Priorities for the future

The full set of questions used can be found in Appendix 9.

This national conversation with the people of Scotland was delivered through the following engagement activities:

Five National, Virtual Events

In partnership with HIS – Community Engagement, the ALLIANCE delivered five national, virtual events with the people of Scotland. People were invited to come together to discuss and share their health and wellbeing experience during the pandemic through a facilitated conversation. Five events were held from Tuesday 20 October – Thursday 29 October, where two where supported British Sign Language Translators and Electronic Notetakers.

These events were attended by 204 people and were positively received by attendees:

“ *Good interactions between participants and facilitators with a wide range of topics discussed.* ”

“ *It was a very supportive and inclusive space to share thoughts and ideas.* ”

Collaboration with Integration Authorities and Health Boards

The ALLIANCE and HIS-Community Engagement contacted the Chief Executives and Chief Officers of all Integrated Authorities and Health Boards in Scotland inviting them to take forward engagement activity in their local areas. This strand was developed and delivered to capture experiences at a local level and ensure geographic spread in the data collected (Appendix 2) and took place between October 2020 and November 2020. To assist Integration Authorities and Health Boards in the engagement process the ALLIANCE provided a facilitation pack, promotional materials, equality monitoring forms and data protection and feedback documents.

Health Boards and Integration Authorities were also invited to contribute findings from relevant, previous engagement activity and/or to share details of the national events and Open Call for experiences.

Partnering with the ALLIANCE’s membership for the People at the Centre Reference Group

From September 2020 to November 2020 organisational members of the ALLIANCE were also invited to contribute their member and stakeholder views and experiences to the programme, to capture experiences across a range of health and social care organisational remits.

As with the Integration Authority and Health Boards, members were invited to take forward their own facilitated conversations, supported by materials and resources provided by the ALLIANCE.

Contributions of pre-existing research undertaken by these organisations were also welcomed, and members were asked to share details of the national events and Open Call for experiences.

Open Call for Experiences

The ALLIANCE also put out an Open Call for experiences directly to the public, enabling people to contribute their views and experiences without attending an event. This Open Call was promoted on social media, by Integration Authorities, COSLA and Health Boards, through the ALLIANCE's networks and via print media. Throughout October 2020 and November 2020 there were three ways to take part in the Open Call:

- Completion of an online survey which was hosted on EU survey throughout.
- Completion and submission (by post or email) of a template Word document.
- Taking part in a 1:1 telephone conversation with a member of HIS-Community Engagement.

Key Population Groups

This project was not specifically equalities focused, however, significant work was done to make it as representative as possible. Taking an Equalities and Human Rights Approach was a founding principle to this work as such an Approach to Human Rights and Equalities was developed, which tracked the involvement of a number of key characteristic groups across the programme. Equality Monitoring data was also collected to capture the degree of representation in the project.

HIS – Community Engagement reached out to their contacts across health and social care to enable engagement with carers groups, young people, volunteers and people living with long-term conditions and disabilities.

To ensure breadth and diversity of perspective in

the programme, the ALLIANCE also arranged five additional channels of engagement for specific population groups.

People with Experience of Social Care

The ALLIANCE partnered with Inclusion Scotland to deliver an event on 9 November 2020 with their People Led Policy Panel to seek the views and input of people who need social care support, including disabled people and unpaid carers.

To support this event the facilitation pack, privacy statement and discussion questions were translated to Easy Read.

Disabled People

The ALLIANCE partnered with Disability Equality Scotland (DES) and their Access Panel members to deliver an event on 10 November 2020.

To support this event the facilitation pack, privacy statement and discussion questions were translated to Easy Read.

People experiencing long COVID

On 11 November 2020, the ALLIANCE held an event specifically for people with lived experience of long COVID to share their views and experiences.

People from Minority Ethnic Backgrounds & Communities and Different Faith Groups

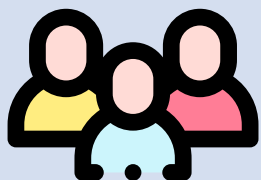
The ALLIANCE held an event for people from minority ethnic backgrounds & communities and different faith groups to share their experiences and views on 12 November 2020.

People who live in Care Homes or who use Care at Home Support

The ALLIANCE partnered with Scottish Care and Care Inspectorate to provide the opportunity for people who live in Care Homes or who use Care at Home support to contribute their views. An online survey, a word document and 1:1 telephone interviews with Care Inspectorate Inspection Volunteers were offered as ways to engage.

Representation overview:

The representation of all protected characteristic groups and a number of additional focus areas were monitored throughout the programme. Some highlights are:



57%
OF PARTICIPANTS

who completed an Equality Monitoring form shared that they lived with a physical health condition, mental health condition or illness lasting, or expected to last, 12 months or more

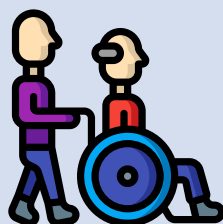
Across these individuals, the following areas were affected:

Vision	4%	Memory	8%
Hearing	5%	Mental health	13%
Mobility	21%	A long-term illness	12%
Dexterity	13%	Stamina, breathing or fatigue	13%
Learning, understanding or concentrating	6%	Socially or behaviourally	2%
		Other	1%



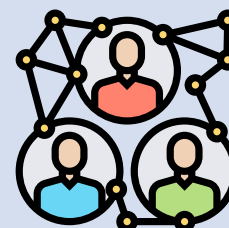
A range of different
FAITH GROUPS

were represented within the programme including: The Church of Scotland, Roman Catholicism, Islam, Judaism, Buddhism, Sikhism, Paganism, as well as those who do not identify as being a part of a religion



100+
UNPAID CARERS

were engaged throughout the programme



8
organisations with a mental health remit engaged with the programme

Of those who completed an equality monitoring form the age distribution was:

5%	WERE AGED 16-29
19%	WERE AGED 30-44
38%	WERE AGED 45-59
30%	WERE AGED 60-74
8%	WERE AGED 75-OLDER

Scottish Care and Care Inspectorate used their networks to promote the various engagement activities to people who live in Care Homes or who use Care at Home Support, to the people who support and care for them and to their relatives and friends.

People who live in Care Homes or who use Care at Home support were invited to contribute directly, and Care Providers and carers were asked, where appropriate, to support people to do this. Where people could not share their own views directly, friends and relatives of people who live in Care Homes or who use Care at Home support were welcomed to share experiences on their loved ones' behalf.

Ongoing partnership with Public Health Scotland

To ensure a collaborative approach across national public health priorities, citizen engagement and the emerging evidence base relating to the wider determinants of health, regular meetings were held with senior colleagues at Public Health Scotland. Discussions focused on themes emerging from PATC engagement, which resulted in sharing of key evidence and learning that has emerged during the pandemic. A full list of the wider evidence shared by Public Health Scotland and reviews as part of this engagement programme is available in Appendix 6.

Community Resilience Best Practice Case Studies

As part of this work the ALLIANCE also gathered case studies from communities and organisations, drawing on examples of local resilience shown during COVID-19. These Case Studies highlight the innovative approaches that have taken place during the pandemic, demonstrating how individuals and communities have drawn upon their individual and collective assets to support the response to COVID-19.

The Community Resilience Best Practice Case Study series can be found at 7.

Health Inequality Challenges and Solutions

As part of this work the ALLIANCE also The ALLIANCE worked with colleagues in RCGP Scotland, the GPs at the Deep End cohort and the Link Worker services across Scotland to develop a living profile of health inequality challenges and solutions. This workstream drew together pre-existing research and evidence, as well as collecting a selection of supporting case studies.

To facilitate this work direct contact was made with CLW Programme Managers from across the country, the Chair of RCGP Scotland and with Dr David Blane (Clinical research Fellow in General Practice and Primary Care, University of Glasgow).

Citizens' Panel

As a part of this programme, Healthcare Improvement Scotland (HIS) Community Engagement engaged with people who use health and care services, carers, and the public through the Citizens' Panel. The Citizens' Panel is a cross section of around 1,150 members of the Scottish Public who were randomly selected to give feedback on health and social care topics. Together the panel members cover all 32 local authority areas and are broadly representative of the Scottish population. The ALLIANCE worked with HIS Community Engagement to align the questions put to the panel with those used in the PATC conversation with the people of Scotland. The questions focused on panel members' own experience of health and social care services and their priorities for health and social care in the near future. The findings from the panel are available in a separate report on [HIS - Community Engagement's website](#).

Appendix 2: Methodology - analysis

Throughout November and December an Analysis Group, made up of nine individuals internal to the ALLIANCE and two external consultants, Dr Emma Miller and Dr Nieves Ehrenberg, analysed the data submitted to the programme.

Data was divided in to five subgroups for analysis:

- **Organisational Feedback** – This subgroup was made up of data captured through (1) the five national events, (2) the Integration Authorities and Health Boards, (3) the third sector organisations and (4) the targeted population events. A qualitative, thematic analysis approach was used.
- **Individual Feedback** – This subgroup consisted of the contributions received in response to the Open Call for experiences. A qualitative, thematic analysis approach was used.
- **Community Best Practice Case Studies** – A qualitative, thematic analysis approach was used.
- **Health Inequality Challenges and Solutions** – A qualitative, thematic analysis approach was used.
- **Equality Monitoring** – This subgroup was made up of data captured through the Equality Monitoring forms and tracking the remit of organisations the programme engaged with.

Each subgroup was made up of a minimum of two individuals to ensure that thematic interpretations were appropriately challenged before being accepted. Subgroups met regularly to facilitate these discussions with support from Dr Emma Miller. The wider analysis group also met regularly throughout October and November to plan, implement and monitor the progression of analysis, as well as to track and discuss the emerging themes from across the programme.

Each subgroup produced a short, internal summary report of the data they focused on. The findings from these reports were then in turn drawn together to form the basis of this final report.

Limitations

The ALLIANCE endeavoured to ensure that all engagement activity was comprehensive and inclusive, but recognises that there have been limitations to the activity taken forward:

- **Time limited project** – This has been a time limited programme of activity which has balanced the requirement for effective engagement, with the need to inform the dynamic and real time re-mobilisation of healthcare services. Whilst the reach of the programme has been vast, it is recognised that some individuals and organisations will have been unable to contribute in the timescale available.
- **Engaging within social distancing guidelines** – As this programme of engagement has been delivered in the midst of a pandemic, methods of engagement were limited to those which complied with national and local guidelines in place. Though some activity has been delivered face to face, and through telephone and postal submissions, data collection has almost exclusively taken place virtually. Therefore, there is a portion of the Scottish population who are unable to access digital technologies whose experiences may not be reflected within this report.

Reach

Through a range of engagement activity, the programme engaged with people from Shetland to Dumfries and Galloway and everywhere in between.

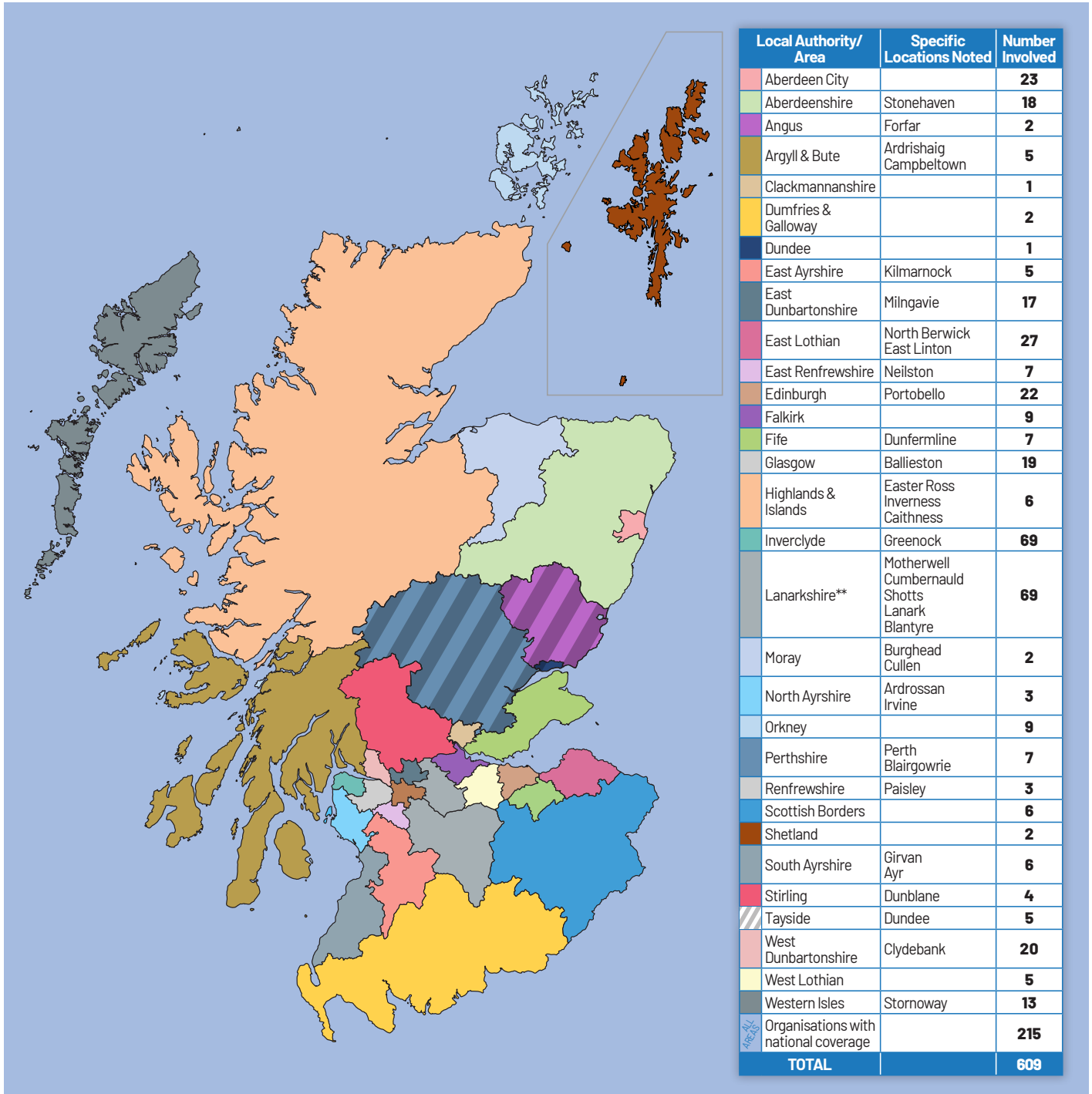
Our aim was to engage and speak to as much of Scotland's population as possible, with a particular focus on those whose voices are not heard as often. Through partnership with HIS - Community Engagement and

Health, Wellbeing and the COVID-19 Pandemic:

Scotland's third sector, we were able to engage with people from all 32 local authority areas across rural and urban communities.

As has previously been shared, this programme also undertook a series of activities aimed at ensuring participation from a wide range of equalities groups.

Throughout this programme, over 600 people took part in conversations held across Scotland:



**Lanarkshire covers North & South as responding organisations cover both authorities.

Appendix 3: Partners

A key principle of this programme has been working in partnership.

Partners and key stakeholders in delivering this project have been:

- Healthcare Improvement Scotland – Community Engagement
- Public Health Scotland
- Scottish Care
- Care Inspectorate
- Inclusion Scotland
- The ALLIANCE membership
- Integration Authorities
- NHS Health Boards

Appendix 4: Contributors

- Aberdeen City Health and Social Care Partnership
- Aberdeen Foyer
- Aberdeenshire Health and Social Care Partnership
- Ability Borders
- Affa Sair
- Alcohol & Drugs Action
- Angus Health and Social Care Partnership
- Argyll and Bute Health and Social Care Partnership
- BEMIS
- Carers Link
- Ceartas Advocacy
- Centrestage Communities Ltd
- Cerebral Palsy Scotland
- Changing Faces
- Clackmannanshire and Stirling Health and Social Care Partnership
- Clackmannanshire Third Sector Interface (CTSI)
- CLAN Cancer Support
- Coeliac UK
- COPE Scotland
- Cosgrove Care
- Cyrenians
- Deafblind Scotland
- Deaflink
- deafscotland
- Diabetes UK
- Disability Equality Scotland
- Dumfries and Galloway Health and Social Care Partnership
- Dundee Health and Social Care Partnerships
- East Ayrshire Health & Social Care Partnership
- East Dunbartonshire Health & Social Care Partnership
- East Lothian Health & Social Care Partnership
- East Renfrewshire Health & Social Care Partnership
- Edinburgh City Health and Social Care Partnership
- Evaluation Support Scotland
- Falkirk Health & Social Care Partnership
- Fife Health and Social Care Partnership
- Glasgow Links Worker Program
- GPs at the Deep End Cohort
- Haemophilia Scotland
- Healthy n Happy
- Hearing Dogs for Deaf People

- Hearing Link
- Hepatitis C Trust
- Inclusion Scotland
- Inverclyde Health and Social Partnership
- Inverclyde Links Worker Program
- Lanarkshire Association for Mental Health
- Lanarkshire Links
- Long Term Condition Hebrides
- Lothian Links Worker Program
- Marie Curie
- MASScot
- Multiple Sclerosis Centre, Mid-Argyll
- Mydex
- National Axial Spondyloarthritis Society
- NHS Ayrshire and Arran
- NHS Dumfries & Galloway
- NHS Fife
- NHS Forth Valley
- NHS Grampian
- NHS Greater Glasgow & Clyde
- NHS Lanarkshire
- NHS Lothian
- NHS Orkney
- NHS Shetland
- NHS Tayside
- North Ayrshire Health & Social Care Partnership
- North Berwick Coastal Health and Wellbeing Association
- North Lanarkshire Carers Together
- North Lanarkshire Health & Social Care Partnership
- Orkney Health & Social Care Partnership
- Pain Association
- PAMIS (Promoting A More Inclusive Society)
- People First (Scotland)
- Person-Centred Stakeholder Group
- Perth and Kinross Health and Social Care Partnership
- Pillar Kincardine
- Poverty Truth Community
- Recovery Enterprises Scotland
- RNIB
- Rowan Alba
- Royal College of Occupational Therapists
- RCGP
- Royal Voluntary Service
- Scotland Versus Arthritis
- Scottish Commission for Learning Disability
- Scottish Parliament's Cross Party Group on Chronic Pain
- Scottish Recovery Network
- Scottish Violence Reduction Unit
- SISCO (Sustainable Interventions Supporting Change Outside)
- South Ayrshire Health & Social Care Partnership
- South Lanarkshire Health & Social Care Partnership
- SSIG (Sensory Impaired Support Group)
- Stirlingshire Voluntary Enterprise
- The ALLIANCE's Self Management Funded Projects
- The Food Train
- The LEAP Project Ltd
- The Minds Well Recovery College
- Voluntary Action Orkney
- Voluntary Action South Ayrshire
- Wellbeing Scotland
- West Dunbartonshire Council for Voluntary Services
- West Dunbartonshire Health and Social Care Partnership
- West Lothian Health & Social Care Partnership
- Western Isles Diabetes Support
- Your Voice Inverclyde Community Care Forum

Appendix 5: Supporting Quotes

This appendix of supporting quotes has been provided to help further illustrate the personal impact and priorities of people who were engaged with. These quotes are not exhaustive but have been included to demonstrate the origins and reflect the nuances of the themes outlined in the report.

We would like to take this opportunity again to thank all individuals who contributed to this engagement.

Access

“ Fed up hearing the NHS is open for business. Nothing could be further from the truth. ”

Digital delivery of services

“ My psychiatry calls have been as regular as appointments in person were. Prefer video calls rather than telephone and rather than in person as less anxiety. Would choose to go once a year in person to maintain that contact rather than losing ability to go at all. ”

“ Anxiety has reduced using this method. ”

“ I worry about how well my needs can be assessed over the phone or a video call... ”

Health deterioration

“ Very worried for family and friends having critical appointments deferred. ”

“ I have suffered pain and distress as a result in missing pain killing injections at usual clinic due to closure. ”

“ The delays for medical appointments, whilst unavoidable, can be a problem for a patient who needs to be ahead of managing a pre-existing condition. ”

“ I feel there is too much emphasis on Covid. Those with existing health problems before Covid started have just been ignored. My symptoms continue to get worse. ”

“ My husbands condition (Alzheimer’s) has deteriorated significantly. He relied on a certain routine which is no longer possible. He has very little understanding of the COVID situation, in particular social distancing. To shop, I have to hold on to him and manipulate him around people, check the shelves and fill a basket. It is incredibly stressful. He cannot be left at home alone, so I am with him 24/7 and it is exhausting. ”

“ Services were cancelled which did not have to be cancelled. Many clinics left sitting empty with no patients. I have been battling with pain for 7 years and to have my appointment cancelled, even though the department is sitting empty (according to the doctor’s secretary) is very disappointing. ”

“ It’s awful I have serious anxiety on top of my normal depression ... and felt alone and just left to deal with having one son locked in his room with covid. ”

“ The amount of services unavailable is ridiculous when we can access food and retail. ”

“ Live alone and feeling isolated. Not identified as vulnerable so unable to access support beyond normal counselling. ”

“ Just trying to speak to a doctor has been stressful in itself. ”

Chest Heart and Stroke Advice

“ The experience of the Chest Heart and Stroke Advice line is they have received an increased number of calls from people who have had a cardiac event or who have on-going respiratory conditions that usually there would have been follow up services after they have left hospital - importance of third sector organisation to step into the gap this creates for emotional support due to the anxiety this creates. ”

Frustration and abandonment

“ COVID has been used as an excuse for the mishaps and slow response to the situation. ”

“ Many services closed and remain closed without real reason, despite the pandemic the response to close everything when there should be access to PPE and the following of infection control is baffling. To consider that I can have a myriad of beauty treatments before going out for dinner with another household but I cannot access dentistry, contraception, essential health checks following giving birth - to only give examples of a few of the services I have been denied - is absolutely shocking and not what I would expect. ”

“ I was due to get an emergency scan done in April but things shut down from there. I have had my GP request this scan four times. The GP hasn't heard. I have not heard. I can't understand why NHS Grampian can't do an abdominal scan. Nobody can put my mind at ease at this. I have had no communication - no explanation, not even an acknowledgement. ”

“ I feel abandoned and ignored by the NHS, and my overall health has definitely suffered. ”

“ I have decided to not try to access my GP any longer as it is hugely frustrating to constantly be told my reason for calling is not an emergency and therefore cannot be dealt with. ”

“ Nobody helped at all, everything was left to partner aged 77 and daughter to provide care and support. ”

“ The stopping of non-essential services means we stopped a lot of prevention work and my long-term condition was physically a mess by the time I could re-access services. That could have been prevented. Some of us got sicker. ”



Communication

“ My only method of contact with the surgery has been via the AskMyGP portal, as the phone is now permanently engaged, but even that has been closed down on several occasions, due to “high demand”. I feel abandoned and not in the least supported. ”

“ I’ve found that it’s surprisingly difficult to find out what we can and can’t do. I finally found the page on the government website, but it was not easy to find. Also I feel that any extra mental health advice seems to be more geared towards those experiencing problems as a result of the pandemic, rather than those whose condition has worsened due to it. ”

“ I am aware that COVID is the number one priority but in the process I have been losing my sight with cataracts, my appointment being cancelled at the start of lockdown. I called and was told nothing would be happening for a while. I am very aware of the present situation but I think there could be a little more communication taking place with those who have had cancelled appointments. ”

“ My mum hadn’t seen her psychiatrist since January. There has been no contact from the hospital and the CPN seemed to have gone off radar...I hadn’t heard for her for going on for 16 weeks until I made the call. It was just like they’d disappeared her and she’d previously seen mum every 2 to 3 weeks and she also had a support worker who went off on long term sick so there was absolutely nobody except [third sector organisation]. There was nobody checking mum’s medication and checking she was ok... nothing. To go from having such regular contact to having nothing has definitely impacted my mum. There is no support or reassurance that she is ok. All that was bottled up for the last 6 months and now she’s back in... hospital for the first time in 5 years. There was poor communication between my GP and the mental health services. ”

Health literacy

“ Health services need to keep people up to date on how they are working and that people haven’t been forgotten (e.g. when appointments were cancelled due to COVID). ”

“ I was due for a post-mastectomy in March – left a phone message on 16th March and didn’t hear, then lockdown happened. Eventually wrote a letter to them 16 April about the 6/52 post op check and said I understood because of COVID about no response but asked if they could eventually let me know what the ongoing procedure would be – I was phoned by a Breast Clinic Nurse in about early June to say I was not forgotten and they would be in touch so that’s been good. ”

“ I don’t know what other people’s experiences have been with hearing difficulties but for me, it’s been extremely inaccessible for me. In the future, we need to protect the phone to text translation service. When everything went to telephone, there was a six to ten hour wait for a telephone. I’ve had my GP service saying there’s nothing we can do even though the NHS does have a video service and they do have ability to make an override in special circumstances. ”

Confusion and Uncertainty

“ The problem is we do not know what services are available to ask for. I happened to know of Hospital at Home but not about the aids I could have got. ”

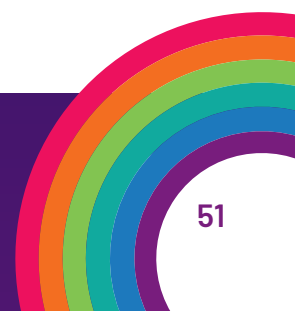
Variable response

“ The system of appointment and consultation by phone used at the Medical Practice was very much easier than the old system of getting a distant time for a physical appointment. The GP was reassuring, but suggested that my husband should go to A&E in any hospital for a check-up. ”

Inclusive comms

“ Deafblind people are becoming increasingly isolated. Communication barriers have increased because of social distancing. Vital service for deafblind people and lack of access to this specialist guide communication service which has been cut over the years has had a negative impact on health and wellbeing. ”

“ Made an appointment to visit my GP for my annual blood test so that I could renew a repeat prescription. I was offered a flu jab at the same time, even though my GP was not providing its usual flu jab clinic. ”



“ Positive experience I have had and I have a catheter and usually go to separate clinic different to my usual GP. The nurses have been in contact as GP district nurses that I used to use for this care they got in touch with me and organised coming to house for the catheter changes during the pandemic. It comes down to that communication again and I have not had to organise this myself. It has been a weight off my shoulders that it was all organised for me as it's not always the case. ”

Variable response

“ The system of appointment and consultation by phone used at the Medical Practice was very much easier than the old system of getting a distant time for a physical appointment. The GP was reassuring, but suggested that my husband should go to A&E in any hospital for a check-up. ”

“ Made an appointment to visit my GP for my annual blood test so that I could renew a repeat prescription. I was offered a flu jab at the same time, even though my GP was not providing its usual flu jab clinic. ”

Health inequalities

Unpaid carers

“ As the parent of an autistic child with learning disability, I struggled when the schools were closed. As long as schools stay open, this helps him with routine and means I can continue to work. Currently, all respite is cancelled so it's even more important to keep schools open. ”

“ Experience has been difficult, with care responsibility for 80 year old mother and my own disability its been trying. ”

“ It was personally difficult to be managing a work from home environment alongside personal caring responsibilities. For me, I was also supporting and organising care for my elderly mother who is affected by dementia. Most of her services stopped overnight because they were not critical. I suddenly became a carer and had to manage this alongside a busy and ever-changing workload. And while I received good support from social work services, it was intense. ”

Maternity

“ Spent 4 days alone in hospital room for induction with no visitors allowed and limited staff. Husband only allowed once waters broke and had to leave immediately following c-section. I was left alone to recover and care for my child with no one available to help me lift, change, feed child. Pain medication was delayed because of limited staff. ”

“ Vital health checks such as 6-8 week mum and baby checks and health visitor appointments should never have been cancelled. ”

“ I think it's disgraceful your only allowed 1 birthing partner and even they are restricted when you're in labour. Due my first baby and that is nerve racking in itself, never mind the pressures of the pandemic. ”

Equitable access

“ I have spent £1700 on medical care since the pandemic began because you can have procedures done privately. ”

“ With chronic pain clinics closed throughout Scotland, no emergency help was provided. That led to some patients having to appeal to England to help them and pay privately, two happenings which are shameful for Scotland... ”

“ I have started doing an online pulmonary rehab bootcamp online, from America. Basically, we're doing it for ourselves, going away and finding it, because that support has not been made available through the health system. ”

“ Unable to be seen at early pregnancy unit when bleeding, advised pre covid I would have been seen but told to wait and see if bleeding got worse - had to pay for private scan to provide reassurance that I hadn't had a miscarriage. ”

Care Homes

“ My grandfather died near the beginning of lockdown, and the staff at his care home kept us all well informed and involved us in decision making. This was incredibly important to us as we weren't able to visit him during the his final weeks due to lockdown, and this made us feel like we were still involved in his life. It was also incredibly reassuring to know he was being so well cared for. ”

People with sensory impairments

“ Deafblind people are becoming increasingly isolated. Communication barriers have increased because of social distancing. Vital service for deafblind people and lack of access to this specialist guide communication service which has been cut over the years has had a negative impact on health and wellbeing. ”

“ Health Centre closed so was transferred to unfamiliar group and distant premises. These GPs did not know background of my son’s disability or medication. Unable to have face to face consultation, they were unable to help when, due to Covid, my son became very depressed and had physical problems which needed changes in medication. Phone consultations were hopeless and unhelpful. ”

Lack of Person Centredness

“ Because I moved to my parents, my GP surgery said I couldn’t get my B12 injection as they couldn’t come to my home as they didn’t cover the town my parents lived in. Because I was shielding, I was not able to come in. I had to write a letter to my GP as the receptionists were telling me I had to register with another GP.

Luckily, following the letter a GP phone back and said they could make an exception as it was causing such a stress for get this sorted. I was lucky my dad was a retired GP and gave me my injection as I was really feeling the effect of it being late. ”

“ When I asked about when contraception services would be available, the worker that I spoke to advised me that she did not have a “crystal ball” and therefore would not be able to advise. ”

“ “She then said she didn’t have time to hear what I had to say and that she only had 5 minutes and would therefore tell me what she was thinking. ”

“ If you are lucky enough to get through <to the GP> on phone ... it is like speaking to a stranger who doesn’t know your medical history. ”

“ My GP could be hundreds of miles away, because of the way we consult them now. You could “see” someone you never met before. A robot would show more compassion. ”

“ Easy access to joined up information! My husband has Parkinson’s, a complex illness in itself and on top of that, I am faced with the complexities of finding the right support and benefits - it’s a maze, at both national and local levels. I want to know I can connect quickly with the people and services we need and be met with compassion and understanding but this is not the reality. ”

Power imbalance

“ I also had a dog bite in May. Did not manage to see doctor (physically) - only online - this was not the same. I have been left with partial immobility in my finger, which I do not believe would have been the case, had I been seen for a face to face appointment. ”

“ Not getting a house visit for my 85 year old dad which resulted in hospital where after treatment for chest infection returned home one week later and passed away next day. ”

Gatekeeping

“ Last week I had a phone call about my PSA blood test. Not a good start as you had to ring the bell and the receptionist was not aware or willing to do the sighted guiding. Thankfully I was with the taxi driver, and he guided me to my chair in reception. When I was called into the doctor’s room, the receptionist helped me and it was fine. I wrote to the GP afterwards to explain that sighted guiding was formalised by the Scottish Government and it was not just me requesting it... ”

“ Getting past the receptionist is very hard. ”

“ GP & hospital because of unwelcoming attitudes & feeling of being a nuisance to an already under resourced system as well as ongoing media bombardment telling us to protect the NHS & basically stay home. The questions & process of going through call handlers & receptionists makes me want to give up & try to manage on my own. ”

Decision making

“ I write as an 83 year old male with a history of cardio vascular disease, cancer and type 2 diabetes. I have a genuine and I believe well deserved feeling of being totally disregarded by NHS Fife since April 2020. ”

“ Telephone GP appointments have been fantastic instead of face to face. ”

“ My call to the local doctor’s surgery was returned by the triage nurse who was able to correctly diagnose my problem and provide advice that has successfully cured it. In future, I would be happy if all initial diagnosis was carried out by telephone or by video conference and only escalated if the medical professional felt it was needed. ”

Lack of Person Centredness

“ The pharmacy and GPs have been fantastic. ”

“ Diagnosis with endometrial cancer followed by quick surgery, treatment consultations and aftercare was magnificent. ”

“ For me the health service has been a lifesaver I had a total abdominal hysterectomy and ovarian cancer removed granulosa of both ovaries and pelvic mass removal I have received the best of care. ”

“ I have found the lockdown dreadful, not being able to do things and meet up with the group has really bothered me, but the Zoom meetings have really helped, the group has really helped me a lot and continues to do so. I really appreciated the positive influence that the group and the links workers have on me and my life. ”
Links worker programme participant

Invaluable links

“ Anxiety has reduced using this method. ”

“ I’d like to say thanks and your weekly calls and emails and the added help with fuel and food packs have helped me keep my chin up and motivated me to keep going at a point in my life when I wanted to give up.” ”
Links worker programme participant

Buffering impact

“ There should be more access to services in charities rather than the NHS for mental health as they are much more responsive and caring. ”

“ Third Sector Interface support, connections, communication and coordination role helped us understand what was needing done and where we could best offer support. So, we focused on our core client needs as others were doing food. ”

“ There is a very supportive Facebook Group that was set up locally when individuals started shielding. There is excellent sharing of information e.g. what services are open, additional shopping slots at supermarkets, people asking if someone can drop shopping off to them (the answer is always yes). NHS Shetland, Use of Social Media for those shielding. ”

Assets to Community

“ I learned how to use my PC properly so I could join some activity groups online. ”

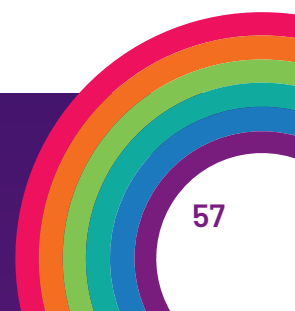
“ Doing my best to think positively, exercise and eat healthier a bit more than normal. ”

“ Resilience group who do shopping for elderly and those isolating. ”

“ Yes, theres a few community groups providing practical support and community online groups for moral Support. ”

“ Community Council brought essentials and at times treats. Extremely grateful and appreciated. ”

“ I think it is shifting people's attitudes and is bringing the 'best' out of most people. This is a worldwide pandemic and proves to me that we have to act together to help save us from complete disaster. ”



Mental Health

“ Feel abandoned and I have to fight for everything on behalf of myself, two preschool children and two elderly parents, all while working more hours than I am paid in NHS. ”

“ I suffered an eating disorder 10 years ago and have found myself struggling with this again. ”

“ My confidence and self-belief are being eroded. A big part of all this is being deaf at this time is more difficult than in normal times. There are good things going on too though and I’m just trying to live from day to day. ”

“ I live alone and have no immediate family so loneliness has been a real challenge and continues to be so. I miss being able to visit friends, locally or further afield, or have them visit me.” ”

“ Has been frightening, lonely and leaves a mark on everyone. ”

“ It has aged me as before I was out most days and now I am losing confidence. ”

“ I see a big impact on the elderly people’s mental health that had been using the common room for company and activities as this has been closed since March in the sheltered accommodation. This has left them feeling very lonely and can see that their cognitive ability is suffering from this as well. ”

“ Life changing, I live alone and not seeing my daughter for months was heart breaking. ”

“ My world is much smaller now. ”

“ I feel I have basically been abandoned and neglected. ”

“ This time has been and is very frightening. ”

Withdrawal from society

“ It would seem when out that people only interested in themselves and putting others at risk by not complying to safety measures, the young especially have a devil may care attitude and high school children during lunch breaks put the whole community at risk. ”

Workforce

“ I had to move out of my home for 2 months because I was expected to continue seeing people with Covid despite raising my concerns that I was living with my husband who was shielding. ”

Services

“ Being dismissed by telephone by the Practice CPN, no follow-up, no listening. ”

“ I wasn't offered any support at all and even although they knew my mental health was going downhill nothing was done until I had to be signed off by my GP with anxiety. ”

“ I couldn't access any mental health help at all. It was utterly impossible and left me completely alone. ”

Digital mental health

“ It is difficult having appointments over the phone as I feel disengaged from the service and have not been offered a near me appointment. ”

“ Online services and information were fab. ”

Wider Wellbeing

“ I am now distraught that <the pool> is about to be taken away from me yet again. ”

“ Yoga for a time was the only thing keeping me sane. ”

“ It's been hard juggling household chores, food preparation, home education and playing with my children. You have to be everything for your children that they're missing. It's very tiring. ”

Workplace

“ More working time at home. not always encouraged and at times prevented. ”

“ Work places not following national guidance and not allowing home working when it was applicable. ”

“ Have worked all the way through and it has been exhausting. ”

“ My work has been good but now expected to attend work rather than work at home even though positive cases on rise and within the care home I to go work at. ”

Person Centred Care

“ Listen to the patients needs rather than always going by blood tests. Tests don't always know how much pain people are in the medications are given out on these blood tests. ”

“ GPs should listen to patient concerns. ”

“ For someone like me who has multiple long-term conditions, a stable and trusting relationship is essential, with someone who knows and understands my problems and who actually *listens* to what I say in the realisation that I've been dealing with these conditions for over thirty years. ”

“ In order to stay well certain things are necessary. Good diagnosis, early correction of problems, support if required. ”

Investment in NHS and Preventative Services

“ Elderly people get a yearly check up with a health practitioner. ”

Investment in Community and TS

“ More funding allocated on a community basis. ”

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Appendix 7: Response to newly presenting need

The third sector and communities have addressed newly presenting need during the pandemic through provision of activities such as:

- Telephone support services/helplines
- Referrals to local Shielding Response Team
- Local food provision
- Referrals to money advice services
- Counselling
- Telephone befriending
- Took note of next of kin and update on system
- Benefits support
- Urgent repairs
- Linking in with community organisations and pharmacies to arrange weekly dispense and weekly pick-up and delivery of prescriptions
- Clothing, bedding and furniture
- Mental health support
- Addictions support
- Respite services
- Financial/debt management advice and assistance
- Housing support.

Appendix 8: Community Resilience Best Practice Partnership Working

a. Coming together to form new entities

A large number of case studies describe the importance and effectiveness of coming together to form new entities in response to the pandemic.

As it became clear that a lockdown was imminent and that vulnerable people would need additional support, our local minister, the Manager of the local YMCA and the Chief Officer of VABS (Voluntary Action Badenoch and Strathspey) came together to create 'Grantown Here to Help.' At the same time a Facebook page 'Grantown COVID-19 Mutual Aid' was created.

Grantown

Another example is the HAART partnership between Angus Health and Social Care Partnership (HSCP), Angus Council and Voluntary Action Angus (VAA) that operated under a vision that no one in Angus would be left unaided. (see HAART Angus)

These new entities created new ways of working effectively across multi-disciplinary teams from different agencies. For example, A&B Caring for People outlines their experience of bringing together a partnership between HSPC, third sector and public health teams because it was identified as necessary to make best use of different partners' strengths across community engagement, delivering care, delivering services and wellbeing support.

They were able to act as a driver of increased collaboration throughout the local community. For example, HAART Angus reported increasing

third sector capacity through collaboration of 20 third sector organisations resulting in a new initiative called Angus Connect, created to ensure a joined up approach across the whole of the Third Sector in Angus.

b. Making use of existing infrastructures:

Ensuring that the community response was effective also required making use of existing infrastructures. For example, the Angus Council Access Line was a well-established and known contact number and the partnership was further strengthened with the addition of the Council's Children, Family and Justice, Communities and Welfare Rights Teams who assisted the volunteers with triage and support as well as frontline delivery. Another instance of this is A&B Caring for People where access to the council's tech team enabled their helpline to operate.

The importance of other organisational infrastructure is emphasised. For example, Grantown Mutual Aid states that without a local community organisation to provide a bank account, governance and financial governance, any community resilience would have been extremely challenging.

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c. Working towards shared vision:

Partnership working was supported by a clear sense that there was a shared sense of purpose and vision driving the work that the partners were doing. For example, HAART Angus stated that the key for the successful initiative and continuous partnership was a shared vision that no one would be forgotten and left in need. The partners embraced the situation, trusted each other's strengths and came seamlessly together to support vulnerable members of the Angus community. They reported that the shared vision allowed a more flexible, holistic approach was also helped remove organisational structural barriers.

d. Virtual communication underpinning successful partnership working

Regular and on-going communication between partners has been crucial to the success of partnership working in many of the case studies and many identified barriers that had to be overcome in order to ensure this communication could take place rapidly and digitally. Many address the need for communication channels to move online as a

result of the COVID-19 pandemic. For example, East Ayrshire Council shared that electronic forms of communication became key, especially in the early stages of the pandemic, as they found their way and put systems in place to ensure support was recorded and the outcomes for any concerns raised.

Whilst there were initial concerns that implementing this work online would be a challenge, the group adapted to meeting online quickly and reported benefits of doing so.

Violence Reduction Unit

The group communicated via a daily Skype huddle during the initial response period. This communication changed to weekly and is now monthly. This regular communication allowed actions to be progressed quickly – as a project, this would normally take several months of planning, but this was such a significant response that Caring for People helpline, local Caring for People teams and volunteers were providing services within 10 days.

A&B Caring People

For Marie Curie, the move to utilising digital communication channels between medical and clinical staff and people who access care and support allowed for the development of new, innovative services which will be continued beyond COVID-19.

A virtual ward was established at our Marie Curie Hospice Glasgow which enabled support for up to five patients with more complex needs being cared for at home. This worked well and included daily input from medical and community clinical nursing teams, Marie Curie Fast Track Service and District Nurses to ensure patients and their families received the support they needed. This innovation will help explore and inform future models of care.

Marie Curie



For regular digital communication and contact to take place there must also be a compatible virtual platform available to use between partners. HAART Angus addressed this by creating new online networks where key partners could come together regularly for discussions and to provide ongoing support.

The team created two online networks which allowed key partners to meet virtually several times a week in order to share best practice, keep focused on the vision and provide ongoing support to each other. These online platforms were Angus Connect, a VAA initiative for Third Sector organisations, and HAART which was a partnership response involving VAA, Angus Carers, Angus Council and Angus HSCP. These platforms were also key to supporting the governance and data collection during this initiative and shared leadership was the crucial to its success.

HAART Angus

Digital compatibility was not the only barrier to regular and on-going communication raised in the case studies however. A&B Caring for People also identified that different governing and reporting approaches were a key challenge to partnership working.

Some organisations shared that in the long term, these digital communication channels will continue to be in place and supplement their previous traditional communication mechanisms.

Going forward, our new ways of delivery will certainly not be a replacement for face-to-face meetings. However, the various continuity measures put in place for COVID-19 will ensure that we are prepared for any adverse weather or even in the event of staff sickness. Delivery can then take place via Zoom to avoid having to re-schedule meetings or pay another member of staff additional hours to deliver at a later date.

Pain Association

e. Third sector acting as a link between community and councils

It was apparent in the case studies that the third sector was seen as a bridge between the statutory services and communities. This came out in several instances, but is well illustrated by East Ayrshire Council, who state explicitly that the motivation for coming together was to make best use of partner's strengths and a key strength of the third sector is seen to be links to the local community.

Another example is Recovery Enterprises, who emphasise the importance of volunteers and community connections and being in a position to engage those who needed support in local communities.

Recovery Enterprises also highlight that community organisations were able to reach many people not known to services despite their level of need. As a local organisation Recovery Enterprises were able to reach out to them and deliver support.

The significant level and nature of our engagement to date has only been possible through unique connections with volunteers. We are humbled in how the community has welcomed us, opening up about their needs and feeling worthless; a community normalising unacceptable standard which we aspire to reverse!

Recovery Enterprises Scotland

In other instances, the third sector was able to develop tools that helped statutory services support people. For example, Rowan Alba created a new risk assessment process using a traffic light system which was shared with other agencies to help plan crisis management. It changed daily and was a quick way of assessing where to put staff resources. Each client consented to a 'what to do if we can't reach you' plan of action.

The value of third sector experience in coordinating volunteers was also highlighted as key means of supporting outreach into communities. In Argyll and Bute, the third sector acted as the volunteer coordinator due to their existing knowledge and experience doing this. For example, almost 1000 volunteers were recruited in A&B, including volunteer coordinators (A&B Caring for People). In Angus, systems were quickly identified and developed to recruit and support 1000 volunteers to deliver prescriptions, provide shopping and/or emergency food parcels and befriending to those most in need (HAART Angus).

It was also apparent that a history of community empowerment and strong third sector links with the community enabled the swift response to the pandemic and supported swift planning and decision making.

East Ayrshire Council

A Community Hub that was created through the Marie Curie Hospice Glasgow service during the pandemic has further expanded external relationships with primary care and is a model that they hope to continue into the future.

The experience of working together has highlighted the value of understanding and respecting the challenges that partners face within their own organisations and appreciating some of the organisational constraints on them.

The collaborative approach was highly successful and ensured person-centred care continued to lead decision making. As a result of the positive impact of the Community Hub on patients, their families and staff, it will become a permanent feature of our Glasgow Hospice services as new levels of normality start to emerge.

Marie Curie

f. Future collaborative working

There is also a sense that an unintended consequence of the situation was that all the agencies involved have accepted that this more collaborative way of working is more effective and there is a commitment to continuing this partnership working going forward.

This has already impacted on how the organisations plan to deliver services in the future. By taking a multi-disciplinary team approach to service delivery, it allows better reach and more successful outcomes for the people of Angus. Building upon this new model, the partners will continue to deliver services to those most in need across Angus. This is a true reflection of our aim to create an Angus that Actively Cares.

HAART Angus



Appendix 9: A national conversation with the people of Scotland – Questions

The questions asked were developed in partnership with HIS-Community Engagement:

Your experience of health services

- Think about the last six months, what has been your experience of health services?
 - What has worked well for you?
 - Is there anything that has not worked so well?
 - Is there any service you've not be able to access?
- Think about the last six months, what has been your experience of mental health services?
 - What has worked well for you?
 - Is there anything that has not worked so well?
 - Is there any service you've not be able to access?
- Thinking particularly about the impact of the pandemic:
 - Are there any services that you yourself have decided not to access?
 - If yes, can you please describe what service and why?
- In terms of your health and wellbeing, is there anything you have done differently to keep well during this time?
- There is evidence of neighbours and communities providing mutual aid and support during this time. Can you share any experiences of this?
- Is there anything else you want to tell us about you experience of the pandemic?

What matters to you? We want to understand what matters to people, what has worked well and what we could do differently in the future.

- Due to the pandemic, there was a greater emphasis on digital access to digital care and using a range of professionals such as pharmacists. Thinking about the experiences you have had, what importance do you place on:
 - Being able to make an appointment online
 - Seeing a health professional face-to-face
 - Getting support and advice to manage your condition
 - Getting treatment closer to home
 - Having general access to services
 - Waiting times
 - Families and carers are informed and involved in decisions about care and treatment
 - 24-hour treatment centres in local communities
 - Of the above, what do you place the most importance on?

What one improvement to health services would make the biggest impact for you or your family in the future/ within the next five years?

Appendix 10: MRG weekly updates

As a part of this programme of activity, 28 twice-weekly updates were also developed and shared with the Mobilisation Recovery Group. These updates shared lived experience of the COVID-19 pandemic collated from a wide range of sources, including research produced by ALLIANCE members and other third sector organisations, as well as emerging insights from our own engagement activities.

- Neurological Conditions
- Stroke
- Cancer
- Respiratory
- Women
- Musculoskeletal Conditions
- Rare Conditions
- Shielding
- Mental Health
- Progress Update
- Autism
- Stroke
- Progress Update
- Care Leavers
- Mental Health
- Recovery Enterprises Scotland Case Study
- Scottish Violence Reduction Unit Case Study
- Children and Young People
- Near Me Public Engagement
- Grantown Here to Help Case Study
- Poverty Crisis Case Study
- Long COVID Engagement
- COVID-19 and Communities Listening Project
- Argyll and Bute Case Study
- SCLD – An Individual’s Experience
- HAART Case Study
- East Ayrshire Council Response Case Study
- Scotland in Lockdown

Updates are available to read on [the ALLIANCE’s webpage](#).

About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. We have a growing membership of nearly 3,000 national and local third sector organisations, associates in the statutory and private sectors, disabled people, people living with long term conditions and unpaid carers. Many NHS Boards, Health and Social Care Partnerships, Medical Practices, Third Sector Interfaces and Access Panels are also members.

The ALLIANCE is a strategic partner of the Scottish Government and has close working relationships, several of which are underpinned by Memorandum of Understanding, with many national NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims; we seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.





ALLIANCE
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