

Health, Wellbeing and the COVID-19 Pandemic:

Scottish Experiences and Priorities for the Future

EXECUTIVE SUMMARY



ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre



ALLIANCE
Insight

The logo features a light blue map of Scotland in the background. The word 'ALLIANCE' is in purple and 'Insight' is in multi-colored letters (red, orange, green, blue, purple).

People at the centre

Introduction

This Executive Summary summarises 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).

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.

The full report “Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future” discusses the findings in more depth and is available on the ALLIANCE’s website. This Executive Summary is also available in Easy Read, Arabic, Mandarin, Polish and British Sign Language.

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 in Full Report) and contributors (Appendix 4 in Full Report) from across the health and social care landscape, inviting them to promote the programme's own activities, or to take forward their own.

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 the report findings, 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 Executive Summary summarises the themes identified from the analysis, which have been informed and supported by a significant proportion of respondents.

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 in the Full Report.

The narrative and emergent themes summarised 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 Full Report and further supporting evidence is available in Appendix 6.

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.

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

Patterns of Experience

Experiences shared during the PATC programme were varied, reflecting the diverse nature of the population of Scotland and people's unique circumstances and challenges during this time. The following patterns emerged from the experiences that were shared across the programme.

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.

- The impact of this lack of access has been considerable and led to a worsening of people's physical and mental health.
- People reported experiencing a number of disruptions which have impeded their access to healthcare services such as paused health clinic, appointments cancellations, increased waiting times and difficulties in making appointments.

“ 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. ”

1. Digital delivery of services

- The digital and telephone delivery of services has enabled people to continue to access health services during this time, and for many the options of remote health appointments provided an easy and flexible approach that was welcomed.

- However, for some people seeing a health professional face to face was felt to be a priority. This was particularly true for people experiencing mental health issues.
- 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 was described in various ways as a basic right that should continue to be available.

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

2. Unhelpful variation in access

- People's experience of accessing healthcare services during the pandemic has been mixed and contradictory, varying with geographical location and across services.
- The experiences shared of accessing General Practice services were particularly mixed. Whilst many people have had positive experiences with General Practice services and shared that they “can't fault services”, 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. ”

3. People’s physical health has deteriorated

- Reduced access to services, particularly those which monitor health, provide ongoing support and keep people well, was shared as resulting in negative implications for people’s physical and mental wellbeing.
- Specifically, people with long term conditions 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.
- 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.

4. 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 have been significant levels of fear and distress amongst people who have had appointments cancelled or their treatment paused.
- 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 and relates, in particular, to the theme below about communication.

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

5. Delivery of, and access to, mental health services

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 the reduction in its availability. This inability to access appropriate mental health support, coupled with the wider stresses of the pandemic has resulted in people reaching crisis point.
- The majority of participants shared that they found the digital delivery of mental health services to be an inappropriate and ineffective model of delivering support, and many people felt uncomfortable using this type of support.

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

Poor communication is a barrier to accessing healthcare

Communication was a consistent theme that emerged across the responses received and could be grouped by those that related to health literacy and inclusive communication.

1. 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.
- Information from Scottish Government and statutory services has been perceived as inconsistent, unreliable and occasionally disjointed between national messaging and local circumstances.

- A common challenge that people have experienced is a lack of effective communication between individuals and their service providers, including being unable to make appointments and receiving unexpected communication.
- Communication to explain changes to care has been insufficient and at times 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.

2. Inclusive flexible communication channels

- 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. Responses also shared that this situation was an issue experienced by people pre-COVID-19.
- People expressed the importance of services adopting flexibility in frequency of communication and communication methods based on choice and individual preference to maximise access.

Health inequalities have been exacerbated and population groups disproportionately impacted

There was a strong sense from across the engagement activities and responses received that underlying problems have been exacerbated by the pandemic.

- 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 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. They also shared that they have not been treated as equal partners in care throughout the pandemic.
- 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.
- People shared the challenges they encountered arranging care and support when English is not their first language. People also reported difficulty accessing virtual health appointments when a translator was required, and some healthcare information and systems were only available in English.
- People who live in Care Homes reported feelings of powerlessness and anger at the implementation of rules and restrictions. They also shared how being unable to have visits with family and friends, to access outdoor spaces, or to take part in social activities within their communities has had a profound, negative impact on their mental health and wellbeing.

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

- However, carers and staff have been praised for their kindness and professionalism during this time.
- Lockdown and restrictions have imposed new barriers for people with sensory impairments including loss of lip reading due to face masks, inability to access appointments accompanied by a support worker and navigating public areas under social distancing guidelines.

- People shielding needed additional support during this time, and the pandemic meant support mechanisms usually in place were disrupted. There was also confusion regarding who should be shielding and how to shield effectively.
- Digital exclusion has also become a prevalent and significant barrier to accessing healthcare for some people in Scotland. There have been many reasons shared as to why an individual may be digitally excluded, such as access to technology, affordability and digital skills.
- There were concerns expressed in responses that inequity of access has widened as people have sought alternate health supports, such as seeking information online to self manage their condition, or accessing private healthcare, options which are not available for all groups of people.

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

Person centred care has reversed rather than progressed

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

- There was a strong desire expressed throughout the range of responses that health professionals and services should 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.

Power imbalance

People have not been equal partners in care.

- 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.
- People have also not been able to make or share in decisions about their care and how they receive it and shared the challenges they encounter when accessing appropriate health services.

“ 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. ”

Responsive services

People have not been equal partners in care.

- People's views regarding their experiences of urgent and emergency services have been overwhelmingly positive.

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

- Most respondents also seemed to agree that pharmacy services worked well for them. 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.
- Community Link Practitioners have also been described by some people and professionals as being essential in supporting people during the pandemic.



Buffering the impact

People described the way in which third sector organisations and local communities responded to the pandemic, and through partnership working, helped to buffer the impact on people and communities. People also shared how they supported their own health and wellbeing and each other during this time.

- The speed at which the third sector was able to adapt and respond, particularly regarding mental health needs and signposting people to available support, was highlighted as a positive that has come from this crisis.

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

- 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.
- Communities have been empowered and impassioned during this time, and community resilience has been demonstrated both formally and informally.
- Throughout the pandemic, organisations, individuals and communities have worked in partnership to provide innovative, adaptable and effective services.

People are assets in their communities

- People have been assets in their communities and to the healthcare system, utilising new self management strategies and ways of keeping themselves well. People have also drawn upon friendships, neighbours and networks for support in creative and innovative ways.

“ 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.



Evidence of the wider impact

As acknowledged by the four harms framework², it is clear from this engagement that the health and wellbeing impact of the COVID-19 pandemic extends far beyond people’s experiences of healthcare services.

Mental Health

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.
- 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. This impact has been particularly significant for those who have experienced bereavement, or who have relatives in Care Homes.

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

- This period of time has also been considerably stressful for frontline workers, particularly those involved in the delivery of health and social care support.

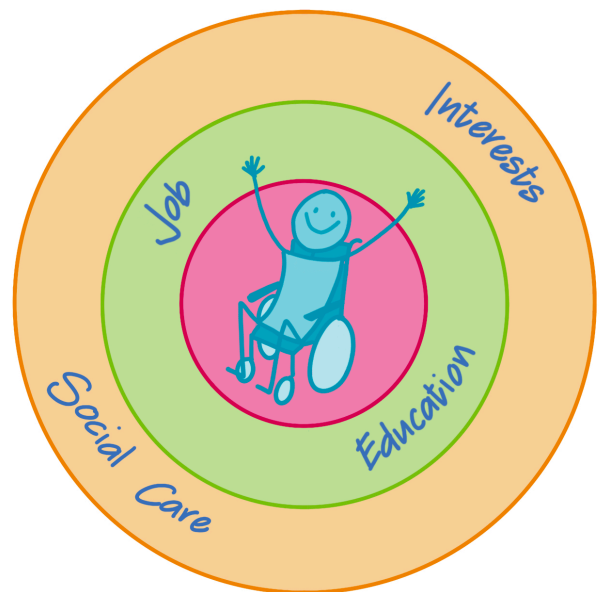
Wider determinants of health and public health impacts

The pandemic’s wellbeing impact extends far beyond the delivery of healthcare services.

- 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.

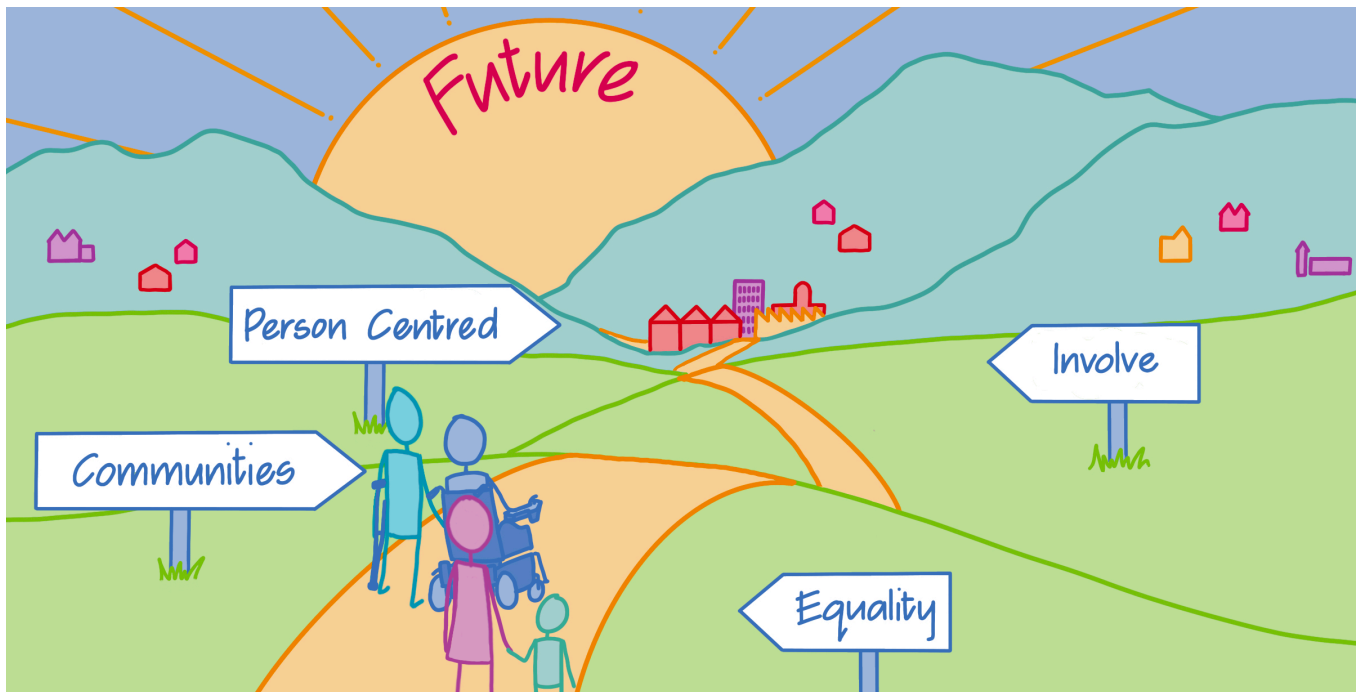
“ Poverty might kill more people than COVID. ”

- People’s work situations, workplace and working habits have also dramatically changed as a result of the pandemic and impacted people’s wellbeing.
- 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.



²Scottish Government (2020) Coronavirus (COVID-19): framework for decision making - assessing the four harms

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.

- 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 responses was the importance

of choice and flexibility. People felt strongly that they should be able to access services, and that the delivery of these services should be adaptable to their specific needs.

Significant priorities which emerged across the programme were:

- 1. Holistic person centred care as the foundation of healthcare services**
- 2. People as empowered partners in decision making**
- 3. Resourcing thriving, vibrant, asset based communities**
- 4. Access to equitable and consistent care**
- 5. Clear, inclusive communication**
- 6. Digital, but not by default**
- 7. Prioritising mental health**
- 8. Investment in the NHS**



ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

Health and Social Care Alliance Scotland (the ALLIANCE)

349 Bath Street, Glasgow, G2 4AA

☎ **0141 404 0231** ✉ **info@alliance-scotland.org.uk**

🐦 **@ALLIANCEscot** 📘 **@ALLIANCEscot** 📷 **alliance.scotland**

www.alliance-scotland.org.uk