

Putting People at the Centre of NHS Scotland Recovery



Introduction

On the 25 August 2021 the Scottish Government launched its NHS Recovery Plan¹ setting out how the detrimental impacts of the pandemic on our country's health service will be tackled. The ambition goes beyond returning the service to pre-pandemic operational standards, it lays out an ambition to go further, to make improvements across several areas by 2026. 'Long term sustainability' is the ultimate aim of the plan, which outlines the steps that will be taken to achieve this.

Fifteen key areas are headlined in the Scottish Government's document including staff and wellbeing, primary and community care, cancer, mental health, innovation and redesign and what the plan will mean for people accessing treatment and support and staff.

Here we set out our response to the NHS Recovery Plan. Having interviewed 11 third sector and civil society leaders² on their views, we consider their responses, capturing their ambitions for the recovery of the NHS in Scotland. We explore the importance of addressing requirements around palliative care in the NHS, how our health service can better treat and support disabled people, the impact of health inequalities pertaining to marginalised communities, and how services can improve health outcomes for children and young people by involving them in service design and redesign, among further themes. We also explore the essential involvement of unpaid carers in the recovery of Scotland's NHS.

Our response also explores current ALLIANCE workstreams including our research report on people's experiences of accessing support for chronic pain, access to GP services across Scotland during the pandemic, our contributions to the Scottish Government's Women's Health Plan, the

launch of the Scottish Sensory Hub at the ALLIANCE, and our policy engagement on Long Covid. Throughout, we identify areas not acknowledged in the Scottish Government's NHS Recovery Plan that, we believe, require specific and appropriate responses throughout and beyond the recovery period.

The impact of the pandemic on all public services but especially the health service has been considerable, and the ALLIANCE welcomes the publication by Scottish Government of its intended recovery plan. However, given that the response to the pandemic has truly been cross-sectoral and the importance of ensuring the recovery efforts respond to the exacerbation of health inequalities, it was disappointing that there was not more engagement with the third sector in the development of the plan.

The ALLIANCE is committed to ensuring the voices of people with lived experience inform policy and practice and to supporting transformational change and have, in part, viewed the Scottish Government's NHS Recovery Plan through this lens.

The culmination of this response to the Scottish Government's NHS Recovery Plan is a set of 18 recommendations. As the national third sector intermediary for a range of health and social care organisations with a focus on involving lived experience in our work, our contribution is a reflection of what is important to our members, partners and those involved in our public engagement work.

The NHS Recovery Plan represents a watershed moment in our history. How we move forward from this point will impact the lives of individuals, families and communities across the country for decades to come. We are not just recovering our NHS, we are securing its future.

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Responding to the Scottish Government's NHS Recovery Plan: Removing barriers, embedding human rights and ensuring equity of access

As a result of our interviews and further research on the recovery of the NHS in Scotland, a common theme has emerged. Every interviewee expressed views that point to the idea that this recovery period affords the opportunity to ensure that Scotland's NHS is accessible to all. It is a period in which current barriers to accessing healthcare, particularly for people who have been marginalised, must be removed and we must prioritise working towards a future in which every person in Scotland's human right to health is upheld, ensuring equity of access across the NHS.

Sensory loss and accessibility of NHS services

One in five people in Scotland live with a form of sensory loss. This includes people living with congenital and acquired forms of Sight Loss, Deafness, people who are deafened, hard of hearing or deafblind. For anyone living with sensory loss, the ability to access and engage with systems rests entirely on the accessibility of that system.

Richard Baker, Head of Policy, Public Affairs and Research at Sight Scotland notes the impact of the pandemic on people with accessible communication requirements: "Sight Scotland runs the Scottish Braille Press and we worked with NHS Scotland to provide information about the pandemic in Braille, but there are still too many gaps. Too often information isn't being produced in accessible formats...we need to have an inclusive communication approach in everything we do throughout our health services."³

A lack of accessibility creates barriers to treatment and impinges on the ability and rights of people accessing NHS services to be active agents in their own treatment and care. To ensure that access to NHS treatment and support is equitable for people living with sensory loss, the ALLIANCE recommends accessibility across every single area of the NHS in Scotland must be at the heart of the Recovery Plan in the next five years.

The NHS Recovery Plan commits to the development of, and investment in, community services including a National Low Vision service and enhanced community audiology services. Setting these services in the community is a welcome measure that, it is hoped, will improve accessibility. Richard points out that the provision of the community based Low Vision service has been a priority for Sight Scotland: "that new service will mean that wherever you are in Scotland, you'll get the support you need quickly after a sight loss diagnosis. It's vital that we recognise the importance of providing rehabilitation quickly as well so people can gain the skills they need to live well."⁴

It must not be forgotten that people living with sensory loss are often living with co-occurring conditions. Many people living with sensory loss are older and consideration must be given to the incidence of dementia in older people and what that means for their interactions with health services. In addition, the mental health impacts of living with sensory loss can be profound. People may therefore be navigating several areas of the NHS at once. This can be a difficult, time consuming process and the impact on people with accessibility needs should be evaluated and addressed to ensure that people do not experience multiple barriers to support that can result in the prevention of engagement with services.

The ALLIANCE has recently established the Scottish Sensory Hub⁵ which will act as a connecting bridge between Scottish Government, the third sector, and the individual. It will enshrine a human rights based approach for all and will focus on three key themes of communication, information and mobility and will look to develop the social model of disability throughout the sensory landscape in Scotland.

The ALLIANCE recommends the social model is adopted as part of the NHS Recovery Plan in relation to sensory loss. In practice that means identifying the exclusionary barriers in place preventing people living with sensory loss from accessing, and being active agents, in the highest level of healthcare possible.



Women's health and the recovery of the NHS in Scotland

Existing inequalities were worsened during the pandemic. The work, some of which was already underway, to improve equality and equity of access to timely, appropriate, and fully supportive healthcare, is now of an urgent nature.

Days before publishing its NHS Recovery Plan, the Scottish Government also published its Women's Health Plan⁶, produced with the involvement of women, in part, working with the ALLIANCE⁷. The Women's Health Plan states that "Women do not always receive equal healthcare to men and that outcomes for women are poorer than those for men." The right to health is a fundamental human right, and the presence of any gender based systemic bias is an impediment to that right being realised. Concluding in 66 actions, the Women's Health Plan must now work in tandem with the overall NHS Recovery Plan to ensure that the health outcomes for women in Scotland are improved in the immediate and long term.

Maree Todd, Minister for Public Health, Women's Health and Sport, said: "We will be really keen to have the voice of lived experience at the heart of that because we want women's voices and experiences to shape the implementation of the plan... then you know whether you're getting it right or not, or whether you need to do more."⁸

The ongoing involvement of women in shaping the future of women's healthcare in Scotland is crucial. It is equally crucial that an intersectional approach to this involvement is taken in recognition that people's identities are not singly experienced and nor are the structural and systemic barriers impacting on them. Therefore, we must recognise the systemic issues that impact on women's health and wellbeing but also recognise the ways in which these systemic issues exist at the individual level from the GP consultation to outpatient clinics and beyond. Women's voices need not only be heard a policy level, but in practice, in the spaces and places where women seek treatment and support.



Including people with learning and intellectual disability in Scotland's NHS

For people with learning and intellectual disabilities and their families, the pandemic presented greater barriers to equality in healthcare. The Scottish Learning Disabilities Observatory (SLDO)⁹ reported statistics showing that, during the first wave of the pandemic, people within the learning/intellectual disabilities population were over three times more likely to die from COVID-19 than those in the general population. This speaks to vast inequality and marginalisation with multifactorial causes.

Charlie McMillan, Chief Executive of the Scottish Commission for People with Learning Disabilities (SCLD) points out that the NHS is one of the most complex systems in our country. It is a system that can prove intimidating, unnavigable, and confusing for people who require support to access it and benefit from it. Those access requirements must be met, particularly as we look ahead to the incorporation of the United Nations Convention on the Rights of Disabled People (CRPD) in Scotland within the current term of the Scottish Parliament. Putting this in the context of the NHS Recovery Plan, Charlie states: "The recovery plan focuses on the system. It doesn't focus on the people who use the system...how do we make sure that those individuals who live in the margins are absolutely front and centre in our thinking?"¹⁰

Acknowledged by Eddie McConnell, Chief Executive of Down's Syndrome Scotland, is the huge impact of the Learning Disability Nursing Network in supporting people with learning and intellectual disabilities to access healthcare and support. For Eddie, however, inclusion must be woven into our overall approach: "We've got to try to imagine and envision a future where actually it's natural for us to include from the outset those whose needs are greater in society, rather than it always having to be a fight from the margins. And I think if we can adopt that more collaborative, real community based, community focused approach, then I think we've got a chance of tipping everything in the right direction and away from the current precipice that we're on."¹¹

The 'precipice' as referred to is apparent in the statistics from SLDO. The ALLIANCE believes that the recovery of the NHS in Scotland from the pandemic must not only safeguard the inclusion of people with learning and intellectual disabilities, it must champion the needs of people who have, to date, too often been pushed to the margins.



The essential inclusion of people from ethnic minorities in Scotland in the recovery of Scotland's NHS

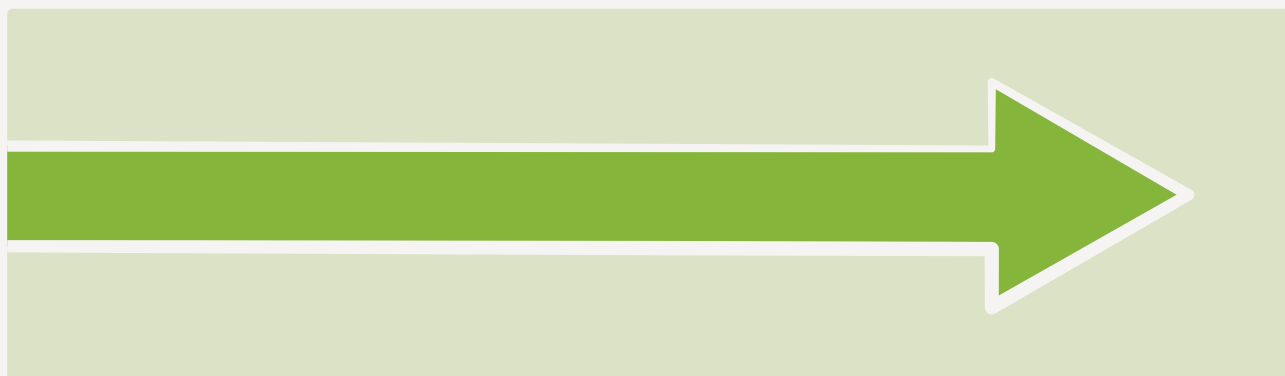
The fact that people from ethnic minority communities across the country were faced with unequal health outcomes in comparison to white Scottish/British people prior to the pandemic evidenced a need for urgent change well before 2020.

Reporting from National Records of Scotland¹² in July 2020 showed that people from South Asian backgrounds were found to be almost twice as likely to die from COVID-19 than white people. UK wide reporting from the Office of National Statistics¹³ showed that people in the Black ethnic group were over 4 times more likely to die from COVID-19 than people in the White ethnic group, after adjusting for age. These figures starkly highlight the exacerbation of existing health inequalities during the pandemic.

Naina Minhas, Manager at Networking Key Services (formerly Nari Kallyan Shango, also known as NKS) spoke to us on the impact of the pandemic in further widening those inequalities: "Inaccessibility increased for everyone, but it increased two or three-fold for ethnic minorities, because of other barriers, because of lack of information, because of lack of support. It kept increasing. Services moved online and the majority of people at grassroots level, South Asians we work with, especially women, older people and families on a low income, they didn't know how to go online."¹⁴

That substantial numbers of people were left behind as a result of the swift, and often essential move, to digital only services across many healthcare settings is a stark reminder that planning for emergencies and disasters must take account of the additional barriers faced by people from minoritised communities.

Naina points out that the NHS Recovery Plan does not include any mention of tackling the inequalities facing the South Asian community or indeed other minority ethnic communities in Scotland and recommends that this be addressed. The ALLIANCE backs this call and, in addition, recommends that people from ethnic minority communities in Scotland be meaningfully included in plans to improve healthcare in the next five years through the Recovery Plan timeframe and far into the future. This requires consultation and engagement that also identifies intersections with race including, but not exclusive to poverty, gender and disability in order to tackle layered systemic oppression.



Giving children and young people a place in designing the future NHS

Children and young people were also disproportionately affected by COVID-19. Research reported by the Scottish Government¹⁵ has shown that for disabled children and young people, and for children and young people living with long term conditions and their families, existing inequalities were exacerbated, there were negative impacts on mental health and there was insufficient attention paid to the rights of children with additional support needs and disability. Not only did these factors have immediate negative impacts, the extended period of lockdowns that restricted access to services and support on an ongoing basis has created an immediate requirement to attend to the resulting health needs of children and young people in Scotland.

The Scottish Government's NHS Recovery Plan puts a focus on the treatment and support of children particularly pertaining to mental health. In addition, the Scottish Government's Mental Health Transition and Recovery Plan, expected to work in tandem with the overall NHS Recovery Plan, includes taking action on areas such as child poverty, children's rights, Getting it Right for Every Child (GIRFEC)¹⁶ and keeping 'the promise'¹⁷ to drive change as a result of the Independent Care Review to improve the lives of children and young people in care.

A renewed focus on ensuring our NHS services meet the needs of children and young people, and particularly of children and young people who are disabled and living with long term conditions, is required. It is important to find ways of including children and young people in the design and redesign of services, understanding what they need and how to create transformational change that will have value to those it has been developed to support.

At the ALLIANCE, we hope that as the Scottish Government implements the delivery of the NHS Recovery Plan that the requisite attention will be given to the experiences of children and young people as they transition to adult services.

The ALLIANCE is supportive of the Principles into Practice Framework¹⁸ developed by ARC Scotland and currently being trialed in various local authority areas. In recent years we have seen notable good practice from third sector organisations, such as Versus Arthritis working in partnership with NHS services¹⁹ to ensure the needs of children and young people transitioning to adult services are fully supported. This example highlights the importance of partnership working between the statutory and third sectors and provides insight into the ability of the latter in supporting the relationships between children and young people and medical professionals in adult services.



Improving services for people living with Chronic Pain

During September 2021 the ALLIANCE conducted a survey of almost 500 people across Scotland who live with chronic pain. In the report entitled 'My Path, My Life, My Right to Live Well'²⁰ respondents were given space to comment on their experiences, putting forward their thoughts and opinions on the essential changes needed in the NHS to better support people living with levels of pain that can be life limiting and psychologically distressing.

Findings from the survey reflected the need for changes in the level of support given to people which was reported by some respondents as being far from adequate. In addition, calls for change including access to specialist services such as pain clinics and around the provision of useful, timely and helpful information for people were made. People felt improvements were needed to clearly inform them on waiting times, treatment options and on condition-specific information such as understanding the chronic pain cycle. Calls for improving continuity of care were also made and some people felt communication from the health services could be enhanced. There are approximately 800,000 people in Scotland²¹ estimated to be living with chronic pain to varying degrees. Every single person's experience is important. The research found that people often feel dismissed and that there is a lack of understanding around the realities of living with chronic pain among providers of treatment and support. People reported reduced quality of life and an impact on their finances.

The powerful testimonies put forward by people in the survey speak strongly to the need to include people with lived experience in the future direction of the NHS in Scotland's approach to chronic pain. The complexities of living with chronic pain must not be underestimated and a focus on supporting the mental health and wellbeing of people is paramount and should be an integral element of the treatment and support agenda for people going forward.



Improving palliative care across Scotland's NHS

Around 58,000 people die in Scotland every year.²² At present one in three hospital beds in the country in acute services is providing care for people in the last year of life. Our NHS is key to people's experiences of dying and, as we move into the recovery from the pandemic, we have an opportunity to assess current practice and make improvements to ensure every person's right to die well is upheld.

Mark Hazelwood, Chief Executive of Scottish Partnership for Palliative Care points out that many people at the end of life access unscheduled care services.²³ While palliative care is not specifically mentioned in the Scottish Government's NHS Recovery Plan, those unscheduled care services are a point of focus. The plan is, in part, focused on reducing admissions and increasing bed capacity. However, for people in the last year of their life who do require admissions via the unscheduled care route, a renewed focus on best meeting their individual palliative care needs is paramount.

It is equally important to take a more planned approach to palliative care. In terms of taking steps to support effective palliative care in the NHS and beyond into the future, Mark Hazelwood said: "Key to that is going to be about having a commissioning and planning focus, about service redesign and collaborative working between the different parts of the health and social care system and including, of course, the independent sector, major providers of social care, and the third sector."²⁴

Now is the time to undertake this work, evidenced by the work of Scottish Partnership for Palliative Care in its 'Every Story's Ending' report.²⁵ Crucial will be putting the voices of lived experience at the heart of the redesign of services, listening to those at the end of their lives and their families to inform a co-produced approach to care in the NHS, enriched and supported by the independent and third sectors.

To move Scotland's NHS forward in its provision of palliative care, the ALLIANCE recommends increased investment in the workforce across acute and community settings, in particular, upskilling existing staff in palliative care and supporting staff to provide person centred approaches at the end of life.



Involving unpaid carers in the recovery of the NHS in Scotland, realising their rights and improving health outcomes

There were an estimated 729,000 carers in Scotland before the COVID-19 pandemic, and it is estimated an additional 392,000 took on caring responsibilities as a result of the pandemic, meaning the total stood at over 1.1 million.²⁶ As many face to face services across health and social care were withdrawn, people stepped in to provide the necessary support to their loved ones, family, friends and community members.

Organisations across the third sector in Scotland supporting unpaid carers quickly adapted services to enable carers to continue to access essential information, updates on the availability and use of PPE as well as emotional support. Later in the pandemic, carer support organisations worked to ensure unpaid carers in Scotland became eligible for vaccination at the earliest opportunity.

The immense amount of work undertaken by unpaid carers in Scotland must be recognised as must the unsustainable nature of the amount of support people across our communities are currently providing. A particular element of providing unpaid care that requires immediate attention as part of the NHS Recovery Plan is the role of unpaid carers in hospital discharge.

The Carers (Scotland) Act 2016 enshrines the right in law for unpaid carers to be involved in hospital discharge of the people they care for.²⁷ Getting this right for unpaid carers and the people they care for is an essential element of improving recovery and health outcomes for people who are cared for as well as reducing the impact of caring for someone after a hospital admission on the carers themselves.

It is therefore crucial that the voices of unpaid carers are given an equal say in the discharge process and subsequent care requirements of those they care for as is their right. In addition, the ALLIANCE recommends involving carer voices in ongoing engagement around improving discharge support and services to improve overall outcomes for unpaid carers and those they care for as well as engaging with third sector carer organisations and networks across Scotland, putting lived experience and third sector and community experience at the heart of the recovery of the NHS.



The importance of putting the voices of lived experience at the centre of Long Covid treatment and rehabilitation in all areas of the NHS in Scotland

People's voices must be universally heard in practice and policy across health and social care. An acute reminder of the importance of listening to those with lived experience comes from people now living with Long Covid. As Jane-Claire Judson, Chief Executive of Chest, Heart & Stroke Scotland (CHSS) points out, people living with the condition provide the very evidence we need to be able to support them: "The people who understand Long Covid best are people with Long Covid, and decision makers in health and social care should be listening to them, and I'm not sure that that's happening as much as it could be. In fact, I could probably go further and say I'm fairly certain that's not happening as much as it could be."²⁸

CHSS released a Long Covid Action Plan²⁹ calling for clear referral pathways throughout the NHS with data sharing between services. A key element of the Action Plan is that it also calls for signposting to CHSS and other community support services, highlighting the importance of the NHS in Scotland operating as part of a wider health and social care integrated network including third sector and community groups.

Jane-Claire Judson refers also to the positive impact of this integration between services when addressing CHSS campaign 'Right to Rehab'.³⁰ This acknowledges that to support people who have experienced stroke or who live with heart and respiratory conditions – or indeed many long term conditions - to live life to the full, their human right to rehabilitation must be realised. The right to habilitation and rehabilitation is recognised under Article 26 of the United Nations CRPD. Approximately 70,000 people in Scotland could benefit from pulmonary rehab but only 9,000 can access it. Instead of limiting rehabilitation support to a predefined number of weeks, rehabilitation should be designed into treatment, care and support pathways to support personal outcomes with the involvement of the third sector and community services.

Through our extensive work at the ALLIANCE engaging with people living with long term conditions, we know that rehabilitation and self management are not linear processes. People living with long term conditions should have ongoing access to the NHS support they need, when they need it, in addition to the specialist input that can be provided in partnership with the third sector. While the Scottish Government acknowledges the management of long term conditions in terms of its 'Principles for Safe and Effective Recovery' in the NHS Recovery plan, the ALLIANCE calls for an immediate focus to be put on the needs of people living with Long Covid, and echoes CHSS's calls for the 'Right to Rehab' to be adopted as an essential requirement going forward.



Involving lived experience and the third sector in the recovery of mental health services

The Office of National Statistics³¹ released figures on the incidence of depression in adults in Great Britain from January to March 2021. The report stated that levels of depression observed during that period was more than double that seen prior to the pandemic. The toll on people's mental health and wellbeing is clear in these statistics, but this is only a snapshot of the mental health landscape. The Mental Health Foundation has reported in-depth on mental health experiences in *Coronavirus Scotland: The divergence of mental health experiences during the pandemic*³² which captures the complexities stemming from inequalities that existed prior to COVID-19.

The recovery of mental health services in the NHS in Scotland must carefully consider the impact of existing and exacerbated inequalities on people's mental health outcomes and proactively seek to acknowledge how these inequalities impact on people's ability to access services as well as their ongoing impact on a person's wellbeing. In the NHS Recovery Plan a commitment is made to including the voice of lived experience and the third sector in the recovery of mental health services. Jim Hume, Director of Public Affairs and Communications at Support in Mind Scotland stated: "I think that's really quite key. With charities embedded in in those communities across the country then they're in a prime position to support NHS staff."³³

Jim also refers to the inclusion of Support in Mind in the Scottish Government's Transition and Recovery Plan³⁴ in the form of weekly stakeholder meetings, giving opportunity to the organisation's depth of experience to inform next steps. This speaks to our aim that third sector organisations working directly with people across Scotland's communities will continue to be given a seat at the table to inform the future of mental health care in Scotland.

Through the ALLIANCE's Health and Social Care Academy³⁵ programme, we support the work of the Early Intervention in Psychosis Lived Experience Reference Group³⁶ which recommends a human rights based approach be at the heart of service design, a recommendation for mental health services that we endorse. By its nature, the group is centred on lived experience and presents a replicable model for the voices of lived experience to input into policy, practice and service design. We call for this level of involvement of people with lived experience across the recovery of NHS mental health services from the pandemic to ensure that services truly meet the needs and requirements of people experiencing mental illness going forward.



Integration of health and social care services for improvements in supporting people living with cancer

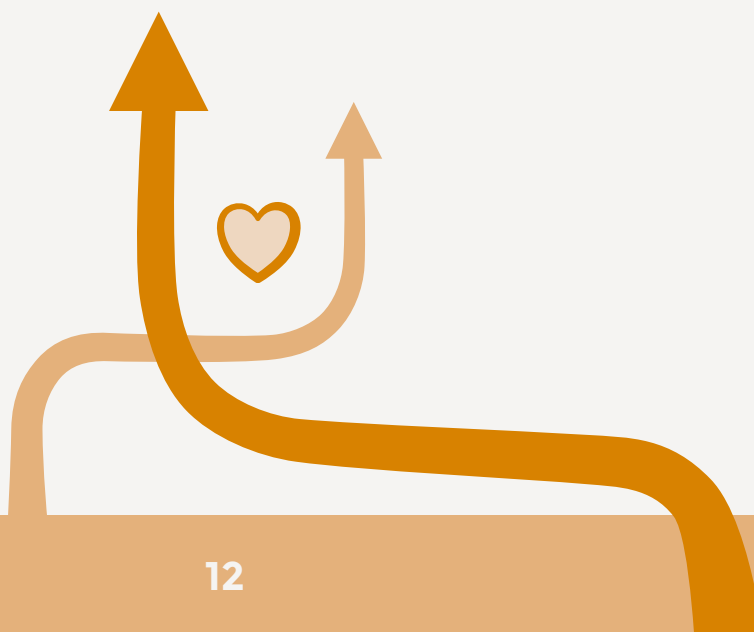
The Scottish Government's NHS Recovery Plan points out that limiting the impact of COVID-19 on people living with cancer has remained a priority and it commits, over the course of the current parliamentary term, to achieving the 62 day cancer waiting times standard. In December 2021 the Scottish Government's Framework for Effective Cancer Management³⁷ was published which acknowledges the challenges emerging from the pandemic.

Identified in the Recovery Plan as a priority is established partnership working with Macmillan in Scotland, which was also given a focus in the ALLIANCE's interview series. In hearing from Gordon McLean, Strategic Partnership Manager at Macmillan Cancer Support, the theme of integration of health and social care services in supporting people living with cancer came to the fore. Gordon states: "In terms of bringing it all together, so that the person has got a single point of contact whether that's within clinical services or within communities services, and actually they're coordinated...that's essentially what we're trying to do."³⁸

Gordon also put a fine point on including the voice of lived experience in service design: "It is essential to our requirements with anything that we are funding through Macmillan Cancer Support that we try to ensure that we've got the user voice very much at the centre both informing and influencing how services should be looking."

The ALLIANCE is working in partnership with Macmillan Cancer Support³⁹ over the next two years to make sure that the needs and views of people affected by cancer continue to inform and influence the redesign of cancer services in Scotland. A key priority until March 2023 is to engage with a wide range of people affected by cancer with diverse life stories and life experiences, with a specific focus on amplifying the voices of people affected by cancer who are seldom heard.

We believe that people's voices should be at the heart of the elements of the Scottish Government's NHS Recovery plan going forward. We are living in a rapidly changing environment and ensuring that we include people every step of the way as we remobilise, redesign and recover services for people with cancer is integral to providing services that meet people's needs.



Developing a digital future for the NHS that works for everyone

As the UK went into lockdown on the 23rd March 2020 the majority of services across the statutory sector, the third sector and the independent sector in Scotland's health and social care landscape had to face the immediate suspension of in person treatment and support. The ALLIANCE's Community in Action⁴⁰ project shared almost 70 reports on the third sector's rapid response to COVID-19 in the months that followed. Most organisations reported a shift to digitally provided services.

The learning across Scotland is an important element of shaping our digital health and social care approach going forward. Key to this is recognising that digital-only services are exclusionary for many people. In the march toward improvement, we must not leave people behind. Transformational change must not come at the cost of people being further marginalised.

There is opportunity in integrating digital approaches and the NHS Recovery Plan touches on several of these including providing mental health support, improving prescribing via digital applications, and the crucial involvement of the Digital Health and Care Innovation Centre. In addition, the Plan lays out its aims for innovation and redesign to support people to digitally manage long term conditions at home, development of which was outlined in the recently published refresh of Scotland's Digital Health and Care Strategy,⁴¹ "Enabling, Connecting and Empowering: Care in the Digital Age". The important contribution of the third sector must be considered as part of these approaches.

Mark Bevan, CEO of Leuchie House which offers short breaks to people living with long term conditions and their families, said his experience of implementing digital strategies to support people during the pandemic has highlighted the need for understanding what really works for people: "I think the very hard and fantastic innovation and energy that's going into digital healthcare is phenomenal, and I also think it's largely focused on data and that's a systems approach, and much needed and important.

"What it doesn't do is enable people to live their own lives in the ways that they want to, today, and there is really cheap readily available technology out there that can make a massive difference. I think if half the energy that went into the very good work that's going on around digital innovation as opposed to enabling technology - if that went into enabling technology now, it would make a huge difference."⁴²



This points to the idea that we must put people at the centre of any digital strategies going forward. Indeed, “people at the centre” is the first of a set of five human rights principles for digital health and social care that have been identified in a piece of work carried out by the ALLIANCE, Scottish Care and VoX Scotland.⁴³ The other principles are “Digital where it is best suited”, “Digital as an ongoing choice”, “Digital inclusion, not just widening access”, and “Access and control of digital data”.

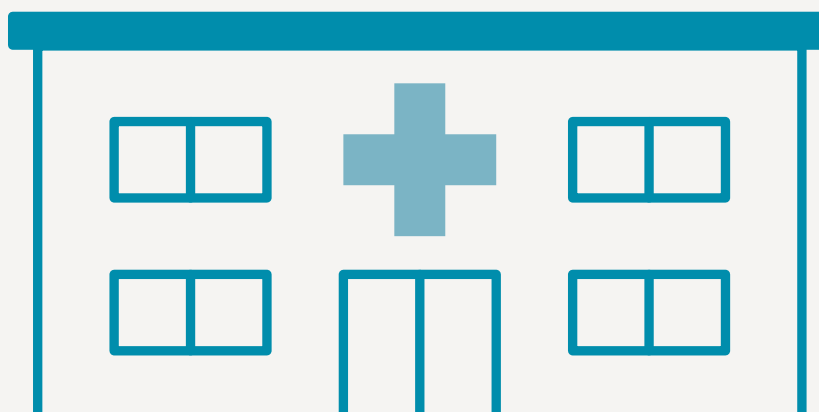
Developers, policy makers and people working to put policy into practice must ensure that there is meaningful co-production as we plan for and operate increasingly digitally based health and social care services. The ALLIANCE’s Digital Health and Care team is leading engagement activity and has established a Digital Citizen Panel⁴⁴ to place people at the heart of design and drive policy and practice. The aim, ultimately, is to shift the power dynamic between government and citizens. The Digital Citizen Panel’s work should be incorporated into the planning processes around the areas of the Scottish Government’s NHS Recovery Plan pertaining to digital improvement.

Relationship building for the future of GP services

GP practices across Scotland have faced huge challenges to maintain levels of treatment and support for people requiring care throughout national lockdowns and beyond. The relationship between GPs, and wider practice staff, and people accessing their services is one that is incredibly important. For many, GPs are the essential step from being unwell to feeling well again and to feeling cared for and supported through longer term illness and conditions. GPs are often the most reliable cornerstone in people’s onward pathways as they are supported and treated in secondary and tertiary care in the NHS.

Given that GPs are most often people’s first point of contact in the healthcare system, any perception of GP services not meeting people’s needs are keenly felt. An ALLIANCE survey conducted in autumn 2021, to be reported on early 2022, gathered responses on people’s experiences of accessing GP services during the pandemic, with just over 200 people responding.

People were asked whether their expectation upon calling their GP surgery was met with almost 65% saying it was and around 35% reporting that their expectations were not met. In addition, we asked about people’s feelings around secretarial and reception staff at practices who were often triaging cases to aid GPs in their work. Some respondents stated that they felt



this function was a barrier to getting the support they needed and that they felt uncomfortable discussing personal health issues with staff who are not GPs. The ALLIANCE fully supports any mechanisms that can be put in place to support any required betterment of the relationships between GPs, support staff and people in their communities accessing treatment and support. It is inconceivable that an event such as the pandemic has not taken its toll in some areas and we must put relationships at the heart of moving on from an exceptionally challenging time.

The ALLIANCE is pleased to note the commitment in the NHS Recovery Plan to give every GP practice in Scotland access to a Link Worker. Our own Links Worker Programme has greatly expanded in the past three years with 58 Community Links Practitioners now working in 65 GP practices in the most deprived areas of Glasgow and West Dunbartonshire. The positive impact of Links Workers cannot be underestimated, providing person centred, community based support to improve people's lives and health outcomes.

The precedent set by the ALLIANCE's Links Worker Programme provides a template to address the health inequalities faced by people, who are often experiencing multiple forms of marginalisation, to contemplate the social determinants of health in the context of the pandemic and in the approach taken to recovery efforts.

Supporting the NHS workforce for a sustainable future

The NHS Recovery Plan puts a focus on staffing and wellbeing. We must recognise the work and sacrifices of NHS staff throughout the pandemic as well as recognising that we are now moving closer toward a full two years of working at crisis level. People are our greatest assets in the NHS and across the wider health and social care system, working in social services and in the third and independent sectors. People are the backbone of every other element of the Service and their health and wellbeing are paramount in the context of recovery.

We can expect little of a system that does not ensure the mental health and wellbeing of its workers is fully supported. Given the traumatic experiences of many NHS doctors, nurses and Allied Health Professionals in facing the realities of COVID-19, the ALLIANCE welcomes the introduction of the new Workforce Specialist Service that is supporting the mental health of staff, and improved funding across health boards via NHS Education for Scotland (NES).

We recommend that there is an 'open door' policy in terms of staff seeking support for their mental health across the NHS, and open to social services, third sector and independent sector organisations working in health and social care in Scotland, and that the confidential supports that are being put in place can be accessed for the full time period required by each member of staff.

Reacting to current and emerging needs of the workforce in terms of support around mental health and wellbeing can only be one element of ensuring that staff stay well in their roles. The ALLIANCE's partnership with Mental Health Foundation Scotland in the form of 'Living Well: Emotional Support Matters'⁴⁵ champions a preventative approach to emotional wellbeing ensuring that supports are pro-actively designed into systems. We believe that this proactive approach must be adopted into NHS systems to ensure the emotional wellbeing of the workforce is protected throughout.

A recovery of the NHS in Scotland built on the voice of lived experience and the expertise of the third sector

The ALLIANCE firmly believes that putting people at the centre of the processes of recovery of Scotland's NHS is a powerful step forward in creating a future for the NHS that fully contributes to better health outcomes and wellbeing across the whole population. We must listen to people who tell us of the barriers they are facing in trying to access NHS services, to those who have an acute understanding of how interactions with a complex system impact on health and wellbeing, and who can explain to us that the ways in which people move through the healthcare system is intricately tied to overall health outcomes.

The NHS Recovery Plan, in practice, must include Scotland's third sector in its implementation. The third sector was an integral part of the response throughout the pandemic, ensuring continued support to communities and individuals across Scotland. The professionalism, expertise, community knowledge, relationships and the ability to work in partnership with the statutory sector positions the third sector as an equal partner in service design and delivery now and into the future. The third sector must be given an equal level of input into the recovery of the NHS in Scotland.

As we move forward into uncertain territory with the ongoing pandemic whilst simultaneously working to implement recovery, it is crucial to acknowledge that the recovery of the NHS in Scotland must be a recovery for all, eminently inclusive and striving to ensure every person's human right to health is upheld.

We must also acknowledge that the recovery of Scotland's NHS is not only about the recovery of a solitary public system, it is also about recognising that the NHS is an integral part of our wider health and social care systems, the whole network of which are key to improving health outcomes and reducing inequalities across all of our communities.



Recommendations

The ALLIANCE proposes the following recommendations for the improvement and recovery of Scotland's NHS to support achieving better health outcomes for all people living in Scotland

- 1.** The meaningful involvement of people with lived experience of healthcare needs, disability and living with long term conditions in all future service design and redesign to ensure their valuable input shapes the services of the future, ensuring an equalities, human rights and intersectional approach is adopted, putting people at the centre of the NHS in Scotland.
- 2.** Full accessibility for people living with sensory loss to be adopted as an essential requirement across all NHS services, including ensuring all forms of communication with people living with sensory loss ensure and enable equitable access to treatment and support.
- 3.** Proactive tackling of the health inequalities faced by people from ethnic minority communities living in Scotland that recognises the particular factors maintaining ongoing marginalisation and seeks to address and dismantle these to improve health outcomes.
- 4.** Mechanisms are put in place to particularly include the voices and needs of disabled children and young people and children and young people living with long term conditions in the design and redesign of services, with a particular priority around supporting the transition from children's to adult NHS services.
- 5.** The work of the Women's Health Plan is adopted into the overall delivery of the NHS Recovery Plan with the explicit aim of reducing the health inequalities that women face and ensuring that women's voices are listened to in practice and in policy now and into the future.
- 6.** Fully recognise and realise the human rights of people with learning and intellectual disabilities as an integral element of all NHS services, removing barriers to accessing those services and upholding their rights.
- 7.** In developing digital services and systems intended to improve and support healthcare, that the NHS in Scotland and the Scottish Government incorporate the work of the ALLIANCE's Digital Citizen Panel and the human rights principles and ensure that people's needs, as expressed by them in research and engagement, drive the design and implementation processes of digital health and care.
- 8.** Prioritise simplifying referral and treatment pathways for people living with Long Covid to ensure they can access diagnostics and treatment necessary to support them whilst prioritising the experiences of people in Scotland living with Long Covid to inform policy and practice.
- 9.** Recognising the greater potential for Scotland's NHS in a public health role in the prevention of adverse health outcomes, tackling health inequalities and supporting everyone in Scotland facing those inequalities to easily access treatment and support to live well.

10. Scotland's approach to chronic pain must be co-produced with people with lived experience, recognising the complexities of living with chronic pain and a focus on supporting the mental health and wellbeing of people as an integral element of treatment and support agenda for people.
11. Continued engagement with people affected by cancer, amplifying the voices of those seldom heard, should be at the heart of remobilising, redesigning and recovering cancer services.
12. To move Scotland's NHS forward in its provision of palliative care, the ALLIANCE recommends increased investment in the workforce across acute and community settings, in particular, upskilling existing staff in palliative care and supporting staff to provide person centred approaches at the end of life.
13. The ALLIANCE recommends that there is an 'open door' policy in terms of staff seeking support for their mental health and wellbeing across the NHS in Scotland and open to social services, third sector and independent sector organisations working in health and social care. It is further recommended that the confidential supports that are being put in place can be accessed for the full time period required by each member of staff. We also recommend that a preventative approach to protecting the emotional wellbeing of the workforce is fully designed into the overall NHS workplace systems.
14. Unpaid carers across Scotland must be included in all work to improve the hospital discharge process, improving health outcomes for people being cared for and those providing unpaid care, also ensuring that third sector carer support organisations and networks operating nationally and locally are involved in the overall NHS Recovery in Scotland.
15. Scotland's third sector must be recognised as an equal partner in the recovery of Scotland's health systems, allowing the sector to bring its expertise, knowledge, community relationships, workforce and ability to work effectively in partnership with the statutory sector to the recovery process in the next five years and beyond.
16. The precedent set by the ALLIANCE's Links Worker Programme should be a template to address the health inequalities faced by people, who are often experiencing multiple forms of marginalisation, in the approach taken to recovery efforts, as every GP practice in Scotland is given access to a Link Worker.
17. A human rights based approach should be at the heart of mental health service design, with the involvement of lived experience of people across the recovery of NHS mental health services.
18. The progressive realisation of the right to rehabilitation is committed to as an essential part of the NHS Recovery in Scotland to ensure that people living with long term conditions have ongoing access to the NHS support they need, when they need it, in addition to the specialist input that can be provided in partnership with the third sector.

- 1 NHS Recovery Plan – Scottish Government <https://www.gov.scot/publications/nhs-recovery-plan/>
- 2 ALLIANCE Live – NHS Recovery Plan series – Third Sector Focus https://www.youtube.com/playlist?list=PLDgTzLd2QrJGP-zgbHvtlxD_P61XoqInY
- 3 https://www.youtube.com/watch?v=ygOcnal31_I&list=PLDgTzLd2QrJGP-zgbHvtlxD_P61XoqInY&index=1
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- 5 <https://www.alliance-scotland.org.uk/policy-into-practice/sensory-impairment/about-us/>
- 6 <https://www.gov.scot/publications/womens-health-plan/>
- 7 <https://www.alliance-scotland.org.uk/blog/resources/womens-health-plan-survey-report/>
- 8 https://www.youtube.com/watch?v=SE5yuUydvVQ&list=PLDgTzLd2QrJGP-zgbHvtlxD_P61XoqInY&index=3
- 9 <https://www.sldo.ac.uk/our-research/life-expectancy-and-mortality/covid-19/>
- 10 https://www.youtube.com/watch?v=IGKj-B6IUUY&list=PLDgTzLd2QrJGP-zgbHvtlxD_P61XoqInY&index=4
- 11 https://www.youtube.com/watch?v=IGKj-B6IUUY&list=PLDgTzLd2QrJGP-zgbHvtlxD_P61XoqInY&index=4
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- 14 https://www.youtube.com/watch?v=_E6AI0EahIY&list=PLDgTzLd2QrJGP-zgbHvtlxD_P61XoqInY&index=6
- 15 <https://www.gov.scot/publications/coronavirus-covid-19-children-young-people-families-evidence-summary-june-2021/pages/2/>
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- 18 <https://www.pn2p.scot/>
- 19 https://www.alliance-scotland.org.uk/blog/case_studies/leading-the-way-on-integration-at-versus-arthritis-in-scotland/
- 20 <https://www.alliance-scotland.org.uk/blog/resources/my-path-my-life-my-right-to-live-well-report/>
- 21 <https://www.alliance-scotland.org.uk/wp-content/uploads/2021/11/My-Path-My-Life-My-Right-to-Live-Well-November-2021-1.pdf>
- 22 <https://www.palliativecarescotland.org.uk/content/publications/Every-Storys-Ending.pdf>
- 23 https://www.youtube.com/watch?v=gXYbSW0G-wg&list=PLDgTzLd2QrJGP-zgbHvtlxD_P61XoqInY&index=2
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- 25 <https://www.palliativecarescotland.org.uk/content/publications/Every-Storys-Ending.pdf>
- 26 <https://www.carersuk.org/scotland/news/covid-19-pandemic-392-000-become-unpaid-carers-in-scotland-in-a-matter-of-weeks>
- 27 <https://www.mecopp.org.uk/mecopp-publications/2018/12/14/mecopp-carers-act-guide-english>
- 28 https://www.youtube.com/watch?v=ztzzTcLp9Uc&list=PLDgTzLd2QrJGP-zgbHvtlxD_P61XoqInY&index=5
- 29 <https://www.chss.org.uk/documents/2021/09/long-covid-action-plan.pdf>
- 30 <https://www.chss.org.uk/policy-and-campaigns/chss-right-to-rehab-campaign/>
- 31 <https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/articles/coronavirusanddepressioninadultsgreatbritain/januarytomarch2021>
- 32 <https://www.mentalhealth.org.uk/scotland/coronavirus/divergence-mental-health-experiences-during-pandemic>
- 33 https://www.youtube.com/watch?v=UtJCeowdJf8&list=PLDgTzLd2QrJGP-zgbHvtlxD_P61XoqInY&index=10
- 34 <https://www.gov.scot/publications/mental-health-scotlands-transition-recovery-summary/>
- 35 <https://www.alliance-scotland.org.uk/people-and-networks/health-and-social-care-academy/>
- 36 <https://www.alliance-scotland.org.uk/blog/opinion/lived-experience-and-the-road-to-early-intervention-in-psychosis-in-scotland/>
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- 40 https://www.alliance-scotland.org.uk/blog/case_studies/#area_of_work=community-in-action
- 41 <https://www.gov.scot/publications/scotlands-digital-health-care-strategy/>
- 42 https://www.youtube.com/watch?v=cIPTz8DEiRU&list=PLDgTzLd2QrJGP-zgbHvtlxD_P61XoqInY&index=7
- 43 <https://www.alliance-scotland.org.uk/blog/opinion/refining-the-human-rights-principles-for-digital-health-and-social-care/>
- 44 <https://www.alliance-scotland.org.uk/digital/get-involved/digital-citizen-panel/>
- 45 <https://www.alliance-scotland.org.uk/self-management-and-co-production-hub/living-well-emotional-support-matters/>

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 over 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, Libraries 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.

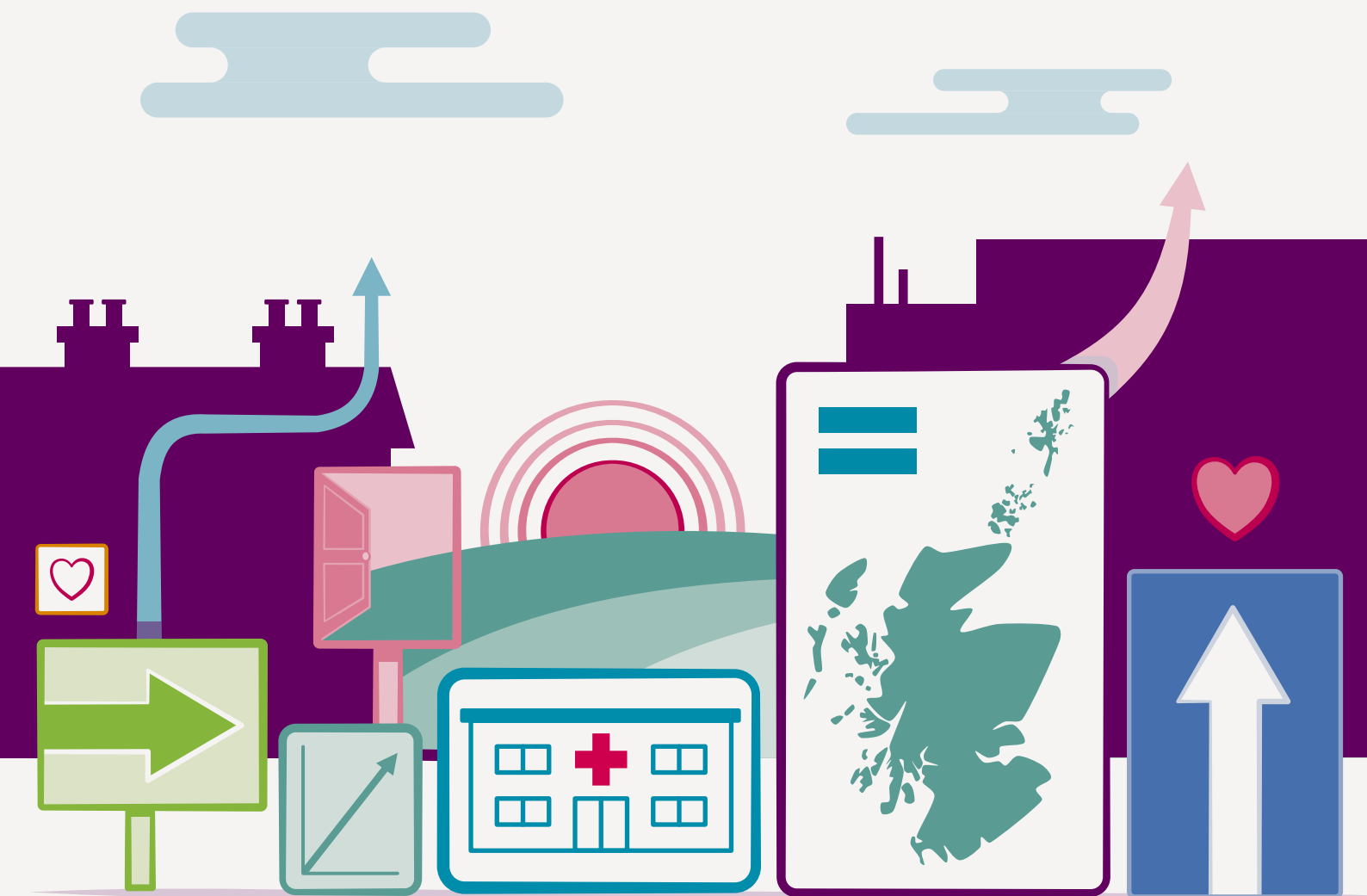
Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

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
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre



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