

**Response: Respiratory Care Action Plan for Scotland
(Draft for consultation)**

3 July 2020

1. Do you agree with the overall vision and aims of this draft Plan?

Yes.

The ALLIANCE welcomes the publication of the draft action plan and the fact that respiratory health is rightly being recognised as a national clinical priority in Scotland.

That said, we believe a more ambitious strategy than that set out in the consultation document is not only possible, but necessary given the significant increase in people living with respiratory conditions¹ which could follow the COVID-19 pandemic.

In particular, the plan would benefit from further detail to ensure that actions are specific, measurable and time-bound. Additionally, in the absence of any mention of financial resource, further information is required on what budget will be required in order to achieve the vision and aims of the plan.

Co-production with people affected by respiratory conditions

Over recent years, the Scottish Government has made efforts to take an increasingly participatory approach to the development of policy, founded on the Christie Commission's priority for public service reform that "effective services must be designed with and for people and communities – not delivered 'top down' for administrative convenience".²

Within this context, the ALLIANCE is surprised and concerned at the lack of direct consultation with people affected by respiratory conditions in advance of the publication of the draft action plan. Whilst the draft is the result of strong clinical engagement, it represents a missed opportunity to put people affected by respiratory conditions at the front and centre, at a crucial juncture for the future of respiratory care and support in Scotland.

¹ <https://www.brit-thoracic.org.uk/document-library/quality-improvement/covid-19/resp-follow-up-guidance-post-covid-pneumonia/>

² <https://www.gov.scot/publications/commission-future-delivery-public-services/pages/2/>

Active involvement in decision making is a fundamental human right, and we believe that people living with respiratory conditions, in addition to the organisations that support, represent and work with them, must have meaningful participation in the development of the associated implementation plan and the oversight of its delivery over its five year lifespan.

Self management

We welcome that self management has been identified as one of the five priorities to be progressed through the action plan. That said, more can be done to embed the ethos of self management across the whole of the action plan, rather than isolated sections.

For example, page five clearly outlines a range of ways that living with a respiratory condition can impact negatively on the health and wellbeing of people and their families. This section contains no reference to any mitigating actions that can be taken, or acknowledgement that with the right help and support, people living with respiratory conditions can feel more in control of their condition and experience an improved quality of life.

Additionally, whilst diagnosis is rightly identified as a priority area, all of the commitments under this heading are associated purely with the clinical based elements of 'early' and 'correct' diagnosis. This section could adopt a more person centred approach by acknowledging the significance of the point of diagnosis in a person's journey, with due consideration given to how diagnosis can be communicated to the person in the most compassionate and supportive way.

2. Do you think we have included the most important priorities in this draft plan?

Yes.

Priority 1 - Prevention

Prevention should absolutely be a priority issue. However, it is unclear how it can be listed as one of the five priorities in this draft, given the fact that none of the 15 commitments made in the plan directly sit underneath this heading.

The forthcoming action plan should make commitments to reducing people's exposure to common risk factors, in the same way that commitments have been made in relation to the other four areas identified as priorities for the plan.

Priority 4 – Equal access

We welcome the action plan's commitment to creating a sustainable environment for the care and support provided by third sector organisations.

Through the cancellation of fundraising events and closure of charity shops, the COVID-19 pandemic is having a significant financial impact on national third sector organisations which provide crucial services to people living with long term conditions. The Chartered Institute of Fundraising has calculated that charities across the UK will face a £12.4billion shortfall in income for the year³.

This impact is being felt at the very time that many third sector organisations face unprecedented levels of demand for their services. For example, Chest Heart and Stroke Scotland has seen an 80% increase in demand for its Community Support services.

The ALLIANCE, alongside over 30 of our member organisations including Chest Heart and Stroke Scotland and the Asthma UK and British Lung Foundation Partnership, has written to the Scottish Government⁴ to call for the establishment of a 'Third Sector Recovery and Renewal Fund' for national third sector health and care organisations. Further assistance such as this is necessary in order for national third sector organisations to support Scotland's response to and recovery from the pandemic.

3. Do you agree with commitments 1, 2 and 3?

No.

Whilst we agree with the underlying aim of commitment 3 below, it needs to be drafted in a way that more clearly specifies which actors are involved in its implementation.

“We will support consistent disease specific pathways and work with the sector to ensure they are embedded in the health services and partners.”

For example, what does “the sector” and “partners” refer to within this context?

³ <https://www.institute-of-fundraising.org.uk/news/charities-are-facing-a-124bn-shortfall-in-income-for-the-year/>

⁴ <https://www.alliance-scotland.org.uk/wp-content/uploads/2020/06/Joint-letter-to-First-Minister-on-Third-Sector-Recovery-and-Renewal-Fund.pdf>

4. Do you agree with commitment 4?

Yes.

The ALLIANCE welcomes the Scottish Government's commitment to increasing access to pulmonary rehabilitation. This has been a campaigning issue raised consistently over many years by our members Chest Heart and Stroke Scotland and the Asthma UK and British Lung Foundation Partnership.

Given the disparity between the current expectation (pulmonary rehab is already a key recommendation within national clinical guidelines that NHS boards are expected to follow) and actual level of provision, it would be helpful for the action plan to provide a greater level detail on the forms of practical support it will make available to boards to address this gap.

Furthermore, the action plan should indicate the amount by which it seeks to increase access to pulmonary rehab, to allow for progress against this action to be transparently measured. The ALLIANCE believes that everyone who needs pulmonary rehab should be able to get it quickly and access proper follow-up support in their community.

5. Do you agree with commitment 5?

Yes.

The ALLIANCE supports action to address variation in both the **quality** of mental health support for people affected by respiratory conditions and the **availability** of such support. However, the way in which this action is currently drafted ("*. . . reduce variation in the quality of mental health support access. . .*") risks conflating these two concepts.

Emotional and psychological support, lifestyle management and peer support should be a key part of the care pathway following a diagnosis of a respiratory condition. The ALLIANCE's 'Emotional Support Matters'⁵ report, published following a series of engagement events with people living with long term conditions and unpaid carers highlighted that people want holistic support that includes emotional and psychological support as part of an integrated service and not just as an 'add on'.

⁵ 'Emotional Support Matters', Health and Social Care Alliance Scotland, 2011, http://www.alliance-scotland.org.uk/download/library/lib_4e3ab46435632/

The 'Emotion Matters'⁶ online training module developed by NHS Education for Scotland and the ALLIANCE aims to address these needs by providing accessible tools and practical guidance to assist health and social care professionals in providing better emotional support. Made up of seven modules, the resource covers subjects such as the range of emotions associated with long term conditions, the challenges faced by a person in adjusting to a long term physical health condition, how to establish good collaborative working relationships, how to better handle distress, and how staff can look after their own emotional health.

6. Do you agree with commitment 6?

Yes.

We welcome to the commitment to improving transitions from children and young people's services to adult services. However, this should be an active consideration for all respiratory conditions affecting children and young people, rather than solely asthma.

The ALLIANCE was commissioned by the Scottish Government to undertake a qualitative study⁷ about transitions to adult services between 2016 and 2017. Based on the experience of 30 individuals and their families impacted by a spectrum of complex and interacting disabilities, the study contains learning and recommendations that may be relevant to the development of this commitment within the action plan.

For example, the study recommended that the 'Principles of Good Transitions 3'⁸ developed by the Scottish Transitions Forum are adopted as the standard approach to transitions across all statutory and voluntary sector transitions services. Additionally, the study highlighted the importance of a 'lead professional' role when there are interlocking services in transition planning.

7. Do you agree with commitment 7?

No.

Palliative care is treatment, care and support for people living with a life-limiting illness, and their family and friends.

⁶ <http://www.knowledge.scot.nhs.uk/home/learning-and-cpd/learning-spaces/emotion-matters.aspx>

⁷ <https://www.alliance-scotland.org.uk/blog/resources/experiences-of-transitions-to-adult-years-and-adult-services/>

⁸ <https://scottishtransitions.org.uk/7-principles-of-good-transitions/>

The statement commits to increasing access to best practice palliative care for people with a lung condition as they near the end of life. Whilst end of life care is an important part of palliative care, people affected by respiratory conditions will benefit from accessing palliative care at any stage of their condition.

The action plan should commit to improving access to best practice palliative care for people throughout all stages of living with a life-limiting respiratory condition.

8. Do you agree with commitment 8,9 and 10?

No.

Commitment 10 is poorly drafted. Whilst one would expect that the intention is to support carers **to access** appropriate information, as currently drafted it could be misinterpreted as a commitment to support unpaid carers **who are** accessing appropriate information. More broadly, the document fails to specify what practical form this support could take.

Commitment 8

Self Management

Self management is a person centred approach in which the person living with a long term condition is supported to access the information and develop the skills they need to feel 'in the driving seat' in relation to their health and wellbeing. Self management does not mean going it alone and is not a replacement for services. The Scottish Government's commitment to self management is established in 'Gaun Yersel' - the Self Management Strategy for Long Term Conditions in Scotland⁹. Developed by the ALLIANCE with people living with long term conditions, it was one of the first examples of a Scottish Government strategy not written directly by the Scottish Government.

As well as access to information, a fundamental element of self management requires a change in culture so that people – those receiving and those delivering services – have the capacity and confidence to work together as partners. The personal relationship that people living with respiratory conditions (alongside unpaid carers and their family) have with health and social care professionals is key to success. The action plan should consider what support and resources health and

⁹ <https://www2.gov.scot/Publications/2008/10/GaunYersel>

social care professionals require in order to more firmly embed a self management approach into their practice.

ALISS

The ALLIANCE manages the ALISS (A Local Information System for Scotland) programme, which helps people to find and share information about a wide range of community services and activities across Scotland that support health and wellbeing. All information in ALISS can be found via the ALISS website (www.aliss.org) which is publicly available online for anyone in Scotland to use to search for support. The ALLIANCE also works with partners to also ensure that the information stored on ALISS can be accessed through other channels. For example, the ALLIANCE has been working in partnership with NHS 24 and Macmillan Cancer Support to embed ALISS data in Scotland's Service Directory¹⁰, which forms part of the NHS inform website.

We welcome the Scottish Government's commitment to the development of the ALISS platform and look forward to working with partners to explore how the resource can further support health and social care professionals and people living with respiratory conditions alike.

Commitment 9

Whilst we welcome the broad aim of supporting the role of technology in enabling self management, this commitment lacks a sufficient level of clarity (or even indicative examples) on what practical steps follow from it or who will be responsible for carrying these out.

One measure that we believe would enable people living with respiratory conditions to participate more actively in the support and services they access would be to provide them with online access to their medical record. This was a commitment made within the eHealth Strategy 2014-17¹¹. It would be helpful for the Scottish Government to confirm whether this commitment is still being pursued, with an indicative timeline for its delivery if so.

9. Do you agree with commitment 11?

Yes.

¹⁰ <https://www.nhsinform.scot/scotlands-service-directory>

¹¹ <https://www.gov.scot/binaries/content/documents/govscot/publications/advice-and-guidance/2015/03/ehealth-strategy-2014-2017/documents/ehealth-strategy-2014-2017/ehealth-strategy-2014-2017/govscot%3Adocument/00472754.pdf>

However, we feel that the action plan should explicitly acknowledge the essential role of Allied Health Professionals in providing support to people living with respiratory conditions.

Allied Health professionals provide system-wide care to assess, treat, diagnose and discharge people across social care, housing, education, and independent and voluntary sectors. AHPs are key to supporting a preventative approach and self management for people living with respiratory conditions.

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 and Medical Practices, Third Sector Interfaces and Access Panels are also members.

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.

For more information

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