The Cabinet Secretary for Health and Sport launched the Scottish Access Collaborative in November of 2017. This will be closely aligned with the Regional Planning, Realistic Medicine, Elective Centres Programme and extant Performance Management and Clinical Priorities, Delivery Activities and Programmes. In the complex landscape of healthcare planning and delivery the Access Collaborative will focus on developing collaborations which build on existing work streams and networks to sustainably balance demand and capacity.

The Collaborative is led by Professor Derek Bell, Chair of the Academy of Medical Royal Colleges, and Paul Hawkins, Chief Executive of NHS Fife and is made up of a range of professional bodies including the Scottish Academy of Medical Royal Colleges, patient representatives and service leaders. The Collaborative has developed six fundamental principles which will shape and prioritise the way services are provided in the future. These principles are described in this report in the context of the findings.

The aim of the Scottish Access Collaborative is to sustainably improve waiting times for patients waiting for non-emergency procedures.

A key strand of the Collaborative’s work is the delivery of the Specialty Group programme, in which a range of experts in clinical specialties undertake a cycle of design-led workshops with the support of the Digital Health and Care Institute.

The Digital Health and Care Institute (DHI) was commissioned to design workshops aimed at producing high level mapping of each clinical area and identifying clinically led and patient centred sustainable improvements. The findings from these workshops will form the basis of a specialty-led Access Collaborative programme delivering solutions to help scheduled care services to sustainably meet the challenges of the future.

The DHI was established as a collaboration between the University of Strathclyde and the Glasgow School of Art and is part of the Scottish Funding Council’s Innovation Centre Programme. It is part funded by Scottish Government. DHI support innovation between academia, the public and third sectors and businesses in the area of health and care.

For more information on the workshops and instances of best practice please see the Collaborative’s blog:

Members of the Respiratory Speciality Sub-Group came from 16 specialists’ areas and 6 different NHS Board areas, giving the Sub-Group both a broad geographic and functional reach. The first step for the workshops was to identify common Respiratory patient symptoms, noting their importance. Issues were mapped for each symptom and areas to focus on agreed. Further discussion around these focus areas led to suggestions for sustainable improvement. These ranged from reducing unnecessary initial, return and follow-up appointments and improving chronic infection and sleep apnoea pathways. Work to further scope these improvements will be undertaken in the coming months allowing a prioritisation process to take place through the Scottish Access Collaborative (SAC). Future work will involve national support to ensure the Respiratory community, along with primary care partners are supported to make the necessary changes to ensure efficient and effective patient pathways are achieved. It is envisaged that the work areas will be taken forward either through the Respiratory community itself or for broader issues which are not specialty specific, be achieved through the SAC Combined Action Group (CAG).

February 2019

Contributors

Executive Summary

1. Preparation
2. Map the Landscape
3. Ask the Right Questions
4. Sketch Solutions
5. Prioritise
Implementation Support

The aim of the Modern Outpatient Programme is to support the development of a Modern Outpatient service which, aligned with the principles of the SAC, will support effective and faster service change to ensure patients are able to access healthcare in a timely manner. This national Programme is well placed to action the outputs from the Respiratory workshops; supporting clinical teams to test innovative ways of working and how positive improvements proven to enable the provision of high-quality care for patients, can be shared and implemented at scale across Scotland.

Clinical Foreword

Respiratory illnesses present commonly to primary care teams, and represent over one third of the acute medical intake of patients in most Scottish hospitals. The ageing population, advances in primary and secondary prevention of cardiovascular diseases, and improvements in acute and chronic management of respiratory complaints means the burden placed on secondary care respiratory units is far greater than ever before. Ensuring patients see the right health care professional, in the right setting, at the right time, continues to be demanding. We face challenges of prioritisation of those patients with serious illnesses; providing access to diagnostic testing to allow primary care clinicians to make independent decisions about their patients; streamlining referral pathways to minimise non-value appointments; and providing robust long term management plans in primary care for patients with chronic respiratory disease. The SAC respiratory group considered a number of pathways for common respiratory presentations, to highlight the issues that face us in the service.

Scottish Access Collaborative Principles

I. Patients should not be asked to travel unless there is a clear clinical benefit, and that any changes should not increase the workload for primary, secondary or social care in an unplanned/unresourced way

II. All referrals should either be vetted by a consultant/senior decision maker or processed via a system wide agreed pathway – value vetting

III. Referral pathways (including self-management) should be clear and published for all to see

IV. Each hospital and referral system should have a joint and clear understanding of demand and capacity

V. Each local system should have a clear understanding of access to diagnostics as part of pathway management

VI. Improved and published metrics including how we record and measure virtual/telehealth/tech-enabled care
The DHI team interviews one consultant to look at common symptom areas and current key issues.

From this interview the DHI team maps out the insights for consideration by the group in the workshop.

We prioritise which symptom to take forward and why. We map where key issues lie within each symptom pathway, and compare regional variation.

From these discussions, the DHI team pulls together a set of maps which show current issues and distills these into a set of challenges.

We prioritise the challenges as a group. People form working groups around challenges and start ideating and developing ways to address the challenge.

**MEETING**

The DHI team interviews one consultant to look at common symptom areas and current key issues.

**WORKSHOP**

We prioritise which symptom to take forward and why. We map where key issues lie within each symptom pathway, and compare regional variation.

**WORKSHOP**

From these discussions, the DHI team pulls together a set of maps which show current issues and distills these into a set of challenges.

**DISCOVER & DEFINE**

**EXPLORE & DEVELOP**
Symptom Profiles

The set of design-led workshops started with the participants agreeing on a small number of Respiratory symptoms they felt were of top priority to deliver maximum impact through service improvements. These symptoms were then mapped describing the current Respiratory services from initial consultation to eventual discharge. What follows are the six symptom profiles which were identified. Each profile is described along with reasons for why it should form an area to focus on.

This word cloud reflects the relative frequency of the most commonly used words in a group of Respiratory referrals from Fife. The data was collected from more than five thousand referrals and was taken from the 98-character field in SCI Gateway. While the word cloud was used for reference only it does support the broad choices of symptoms made in the workshops.
Chronic Cough

Chronic cough generally refers to persistent cough lasting for more than three weeks. It represents a very large number of referrals for Respiratory services and in some clinics, this can be up to 20% of the remaining referrals once sleep related referrals are removed.

**WHY FOCUS ON THIS**
Chronic cough is a symptom that can cause great anxiety for patients but for which little can be done currently in clinics to improve it. This symptom is recognised as a significant issue for a patient and therefore could be a good target for improving patient experience. There is regional variation in practice and therefore an opportunity for a nationally agreed approach to the treatment of chronic cough. There is an opportunity for more support and advice to be made available for primary care when considering care options. The definition of what constitutes a chronic cough could be agreed and defined before addressing its issues.

Shortness of Breath

Shortness of breath where the patient cannot breathe properly represents a sizeable number of referrals into Respiratory secondary care services and a significant number of patients.

**WHY FOCUS ON THIS**
Shortness of breath is a symptom shared between Cardiac and Respiratory pathways. At the moment patients can go from one speciality to another as diagnoses are ruled out. This adds to waiting times for patients as they move back and forth between secondary and primary care.

Somnolence (Daytime Sleepiness)

Somnolence is when a patient has an abnormally strong desire to sleep or will sleep for longer periods of time than is considered normal.

**WHY FOCUS ON THIS**
A large number of patients present to Respiratory services with Somnolence. In some cases, sleep related referral represents 50% of all referrals. There can be variation in the service patients receive depending on where they are in the country. Of the patients presenting with this symptom less than 10% will need treatment to avoid serious repercussions. There is potential for streamlining this service to screen incoming patients and re-design the way sleep studies are handled by secondary care.

Chest Pain

Chest pain is described as an acute or chronic pain felt anywhere in the chest. In Respiratory services the type of chest pain that is of significant interest is pleuritic chest pain.

**WHY FOCUS ON THIS**
Chest pain sees a relatively small number of referrals however, for the majority of Respiratory referred chest pain, there is little that can be done for the patient if the cause is actually musculoskeletal. A large number of chest pain referrals into Respiratory services could be better directed to another service. Referrals of younger patients with some pain that fluctuates in its intensity is mainly not deemed to be serious after examination and diagnostics. The issue for Respiratory is that the definition of chest pain does not offer the distinction between pleuritic and other chest pain, hence the inappropriate referrals.

Haemoptysis

Haemoptysis is a symptom whereby the patient coughs up blood. It represents a small to medium number of referrals for Respiratory. In Respiratory terms, haemoptysis should relate to persistent coughing up of blood rather than a single event.

**WHY FOCUS ON THIS**
The symptom has a specific link to suspected cancer. Currently, there is variation in the service nationally, mostly in terms of how the GP diagnoses the symptom. There is variation in terms of following guidelines in primary care and this may result in inappropriate referrals which lead to unnecessary hospital appointments. In many cases, once diagnostics have eliminated serious conditions then the patient just needs reassurance.

Frequent Chest Infection

A frequent chest infection refers to a persistent or severe infection of the lungs or a high number of infections over the course of one or two years.

**WHY FOCUS ON THIS**
In some regions, frequent chest infection referrals are increasing at a rate larger than other symptoms creating an increasing demand on resources. The group agreed that one key issue is that there is no commonly agreed and used definition for this condition. This symptom offers a good opportunity to develop a screening process to pick up on early stage problems and treat them sooner avoiding unnecessary appointments.
Outputs and Actions

The next step involved collaboratively prioritising what to focus on in the workshop. The group identified and located key issues, and the DHI team developed a series of maps illustrating these. Many of the maps clearly show important and challenging areas for more than one symptom, region or service. They therefore represent key opportunities for improvement which if addressed could deliver significant impact for patients and staff.

In the following workshop the participants considered the challenge areas in the issue maps and identified and developed suggestions for improvement. Some improvements apply to more than one symptom pathway and if successful could have significant potential for sustainably improving the balance between demand and capacity.

It should be noted that some suggestions for improvement will have a greater impact when implemented together with another option. For example, improvements in vetting coupled with agreed referral guidelines could have a significant effect on the volume of referrals into secondary care.

Each challenge area was addressed by a multi-disciplinary team from the workshop, with any suggestions presented back to the whole group for validation and wider input. The following pages describe these areas and the corresponding suggestions. These will now be put forward as priority areas of focus for Respiratory and candidates for further development and scaling through either existing national programs of work, or as specific pieces of work within the Scottish Access Collaborative.
A: Lack of clear referral criteria

This issue map describes discussions on referrals for somnolence. This issue was also mentioned in discussions around chest pain and frequent chest infections. There are a lack of clear referral criteria because while the symptoms of tiredness and sleepiness are common they are not always due to Obstructive Sleep Apnoea Syndrome. This leads to inconsistent and variable referral quality and some patients being referred unnecessarily to secondary care. Symptoms such as snoring, frequent apnoeas, and gasping for breath without daytime somnolence are not treatable within respiratory sleep services and such patients will not benefit from being placed on this pathway. There are clear pathways for a variety of non-respiratory symptoms related to sleep, parasomnias such as sleep walking, sleep talking, difficulty sleeping, and narcolepsy, but many end up at sleep clinics unnecessarily and could be filtered out.
B: Fragmented secondary care service

Patients who have been referred with somnolence can experience long waiting times between appointments within secondary care. One example given during the workshops was the time involved to undertake a sleep study and treatment where currently patients wait approximately 8 weeks to get a sleep study, 6 weeks for results, then another 6 weeks for treatment. There is an opportunity to look at services and make them more efficient. This links to having referrals with more patient information, and associated pathways so consultants can make the right choices and get patients the right care quickly.

Suggestions

- Primary care clinicians need good consistent guidance including treatment and continuous advice for patients on their condition.
- The use of nationally agreed guidance and adoption of levels of investigation in primary care would help to promote best practice and avoid patients being seen when it is not necessary.

Secondary care could put in place a protocol where by, at the point of vetting and under certain criteria, the first advice given back to the GP is that patients do not drive. This measure is put in place as a safety measure. However, it was recognised that preventing someone from driving has a significant impact on a patient’s livelihood and social situation. Therefore, quick diagnosis and treatment are imperative.
HOW MIGHT WE remove unnecessary appointments for haemoptysis?

Haemoptysis, or coughing up blood, is quite a common referral to secondary care respiratory clinics. The chance of cancer is relatively low and in many cases this symptom is related to an infection, or trauma from coughing, and is self-limiting. Patients who have cancer may have this symptom however if patients who do not have cancer could be identified earlier this would avoid unnecessary and non-value-added appointments. CT scanning has a high sensitivity for lung cancer, yet access to CT scanning for patients with haemoptysis is limited to secondary care teams, resulting in delayed access to the definitive test, and unnecessary steps in the pathway before access to the CT scan. A reassuring CT scan following self-limiting haemoptysis is likely to avoid the need for a secondary care referral.

Suggestons

- Advanced vetting for secondary care should be recognised in job planning for consultants. The aim would be to help screen out low risk haemoptysis giving more flexibility in seeing urgent suspected cancer.

- GP could request CT scans for patients with this condition, avoiding a visit to secondary care for the patient. This requires a national discussion involving radiologists and integral guidance for GPs if it is to be nationally adopted.

The symptom has a specific link to suspected cancer. The suggestion was that the national guidelines for referral and vetting for cancer would benefit from clarification and national agreement.

Shared decision making with patients or active care, was suggested as an improved underlying approach to patient care. Pathways should involve shared decision making where it is appropriate. An example of this would be if a suspected cancer patient after investigation is found to have Interstitial Lung Disease ILD, the patient should be consulted and options considered, rather than automatically being put on a pre-defined pathway.
Variation in practice within primary care for chronic cough and chest infection was described during the workshop. In the case of Chronic Cough, everything that is done in secondary care could be done in primary care. Making protocols available for primary care to support this shift could bring treatment forward by up to 18 weeks and remove the need for a referral to secondary care. If information to reassure patients that normal primary care investigations rule out a sinister cause was readily available, referrals to secondary care could be prevented.

For recurrent chest infections, secondary care need to see the majority of these patients. All patients get the same diagnostic tests as part of their investigation. If they are done in secondary care at the first appointment this adds unnecessary time to the process. If primary care carry out the test prior to the clinic appointment, the consultant can look at the results in clinic, make the diagnosis earlier, and prevent a review appointment.

**Suggestions**

- For Chronic Cough, develop a new protocol that defines steps for primary care to take in order to start and review treatment before a referral to secondary.

- The protocol should include information for patients to reassure them that primary investigations are capable of ruling out worrying pathology.
Suspected frequent chest infection invariably ends up in the infection clinic and is diagnosed after testing. This issue described here relates to Bronchiectasis which needs an annual review but as yet there are no pathways in primary care to do this so all follow up appointments come back to secondary care. This results in follow up appointments taking place in clinic taking up time for new patients or more complex cases. Primary care could be better supported to manage these patients’ follow up appointments. Chronic disease management has been successfully transferred to primary care in the areas of asthma and COPD, using community specialist nursing models that could be easily transferred to the area of bronchiectasis.

**HOW MIGHT WE reduce the number of unnecessary return and follow up appointments?**

Suggestions

- Enable more follow up in primary care while allowing for speedy access to secondary care when it is needed. An ‘open return’ system was discussed.
- Secure more consistent ring-fenced long-term funding for specialist primary care nurse led services. This was not recommended to cover long term community service for Respiratory conditions such as bronchiectasis and ILD.
- Arrange direct access to quality spirometry through the GP by specialist nurses. If this is taken forward and delivered it would require good quality nationally agreed guidelines which are used consistently. Spirometry is crucial for both diagnosis of COPD and follow up monitoring.
- Change the protocol to one of diagnosis, followed by referral to specialist service in a primary care setting for follow up and review and monitoring.
- Agree national guidance for follow up appointments for Bronchiectasis and ILD in terms of when it should happen in the patient journey, and what should happen in the appointments.
Other Ideas

Shortness of breath is a symptom shared between Cardiac and Respiratory pathways. This is a good candidate for a joint clinical pathway between Cardiology, Respiratory, and potentially Physiotherapy. It is currently a service with many sequential referrals, where patients can go from one specialty to another as diagnoses are ruled out.

This adds to waiting times for patients as they move back and forth between secondary and primary care. There is potential to innovate the current service with the introduction of a joint pathway which would reduce appointments and significantly improve patient experience.

Streamlined sleep service flow (from Dumfries and Galloway):

- Referral from primary care vetted by consultant to return anything that seems obviously not sleep apnoea (parasomnias, essentially).

- 6 week wait.

- Monday: patient comes to see the nurse who completes questionnaires, examines patient, etc. They go home with their sleep study machine that night.

- Tuesday morning: return the sleep study machine.

- Tuesday afternoon: clinic appointment with the nurse who has interpreted the sleep study and tells the patient if they need a CPAP machine or not.

- Follow up is carried out remotely via connected technology.
Next Steps

The Respiratory Speciality Group workshops generated broad agreement on the areas most likely to make a difference to patients presenting with Respiratory symptoms. The recommendations detailed in this report will now be taken forward with national support via the Respiratory community itself, or where the issue is not specialty specific, through the SAC Combined Action Group (CAG). The CAG’s purpose is to address cross-cutting areas of challenge. This further work will begin immediately and bringing together primary and secondary care will work to achieve efficient and effective patient pathways for patients.

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<td>National Guidance for Bronchiectasis and ILD</td>
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<td>Follow-up in Primary Care</td>
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