Connected Health Cities

End of Project Report

Clinical Pathway:
Chronic Obstructive Pulmonary Disease (COPD)

CONTENTS:

April 2020
Professor Mike Pearson

ABSTRACT:

Chronic Obstructive Pulmonary Disease (COPD) is the second most common cause of an acute medical admission, and NICE guidelines suggest many of these could be prevented or managed without attending hospital.

COPD is slowly progressive. Most admissions are in people who are breathless on mild or minimal exertion, who are 60 or older, and who come from more deprived backgrounds.

CHC set out to identify COPD patient cohorts, characterise them, examine their prior and later history, and also where admissions were coming from. We used all recorded diagnostic coding related to COPD, not just primary diagnosic codes. We worked extensively with clinicians to determine all codes.

The project, built on a previous algorithm making use of **all** the diagnosis codes in the Secondary Uses Service (SUS) dataset. 45% more admissions were identified compared with other healthcare applications e.g. NHS Digital or RightCare, who use primary coding only.

The additional patients found in our extract using all diagnostic codes tend to be older, sicker, with more readmissions, and come from deprived localities.

Reports created for each trust were based on their hospital catchments ie. the functional NHS unit and shared with the hospital trust clinical and managerial teams.

Responses to the report from clinicians confirmed that the cohort identified by our algorithm is a more realistic description of their workload.

Using geospatial statistical techniques, it was possible to identify one or two localities (or about 10,000 people) with clusters of high COPD admission rates controlled for age and sex. These hotspots are typically served by 3-5 GP practices.

Examining the hotspot in detail shows they are extremely deprived, admissions tend to be younger, more frequent, and have markers to suggest they have less serious exacerbations.

Discussion with some local CCG teams showed these areas to have less developed service provision for a population with least ability to cope themselves.

Two CCGs are planning whether a focus on the hotspot could develop a local integrated care pathway, that would have greatest potential gain for least resource input. Work is ongoing.

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Overall admission rates continue to rise year-on-year (in line with national trends) and this data can, not only monitor change, but also point to where investment is most likely to be of value.

We also showed that a new more efficient and cost effective inhaler recommended by The National Institute for Health and Care Excellence (NICE) and by all CCGs to the frontline had a very slow uptake; with 15% of practices not supplying a single one three years after the guidance was issued. Our data demonstrates that working in areas of the most need in the first insance may lead to greater opportunities to improve services and patient outcomes.**OPPORTUNITIES**

1. Work with the integrated care system and invite the hospital (and its outreach service), primary care and community services to come together to address the 'hotspot' in particular.
   Invite them to create a focused local approach to their hotspot. This work has already taken place in Cheshire and Merseyside, where hot-spot information has been shared and an approach to support GP practices, however greater attention could be givento hot-spots in the future.
2. Implement the algorithm in the local hospital to:
   a. Make fully up-to-date reports of changing admission rates available – with information on which types of patients may be being affected.
   b. Create prompts for ED staff and others to enable patients to be on the best local pathway at the earliest point in their exacerbation – and automate alerts to those who need to know.
   c. Create evaluations of the local service provision with a view to efficiency and effectiveness of teams – intending to inform rollout to areas beyond the hotspot.

INTRODUCTION:

The model for a Learning Healthcare System (LHS) for the North West Coast (NWC) pilots was to first establish a Trusted Research Environment (TRE) hosting anonymised hospital administrative data for the whole region.

This data was made securely and remotely accessible to a team of university-based data scientists working closely with front line NHS teams.

Each of three pathways (alcohol-related liver disease, COPD and epilepsy) shared a common core aim – to develop methods to leverage greater insight from currently available datasets and to share this information with the healthcare system.

Crucially, the projects were developed 'bottom-up' and iteratively with direct engagement with those delivering care.

The methodologies and results were shared with those delivering care and key players in the local health economy, seeking to bring new approaches to enabling, monitoring and guiding local quality improvement initiatives.

The work focused on providing new analytical tools to enhance the health care system's ability to accurately track emergency care pathways, identify variation and its drivers and opportunities for improving care.

Having established novel analytical approaches to the use of administrative data, CHC then explored opportunities to enhance the analytical tools through linkage to other datasets including primary care and by applying emerging alternatives to traditional statistical approaches (eg. machine learning).

COPD is a chronic disease that is most often the result of prolonged cigarette smoking. By the year 2000, less than 10% of social class 1 people smoked compared to 50% of those in social class 5, demonstrating a significant health inequality.

Those who took up smoking in the 'boom years' are now in their 60s and 70s, and many now have reduced lung function which impacts on their quality of life.A simple viral infection can lead to uncomfortable breathlessness, and often hospitalisation. Acute exacerbations of COPD are the second most common cause of admission to medical wards and represent a huge cost to the NHS.

The NICE guidance for managing COPD shows that there are many options that can reduce admissions – stopping smoking (even at a late stage in the disease), appropriate inhaler therapy (and help to enable it to be inhaled properly), pulmonary rehabilitation courses, home oxygen (for the most severe), and creating a plan to cope when crises arise.

Putting in place such actions is challenging in the more socially deprived areas where most continuing smokers are found, there is more air pollution and where, not only is health provision least well developed, but also there is least resilience to cope in poorer quality housing with less resources.

A healthcare plan requires the primary care team (GPs and their practice healthcare staff), social support from councils, and outreach from the specialist services.

'Integrated care' has been an objective for many years, but in many areas challenging to implement.

The objectives of CHC were to create the data that would, quantify patient numbers and geography in relation to care provision..

These data, could facilitate services to come together and develop services so that these COPD patients would have fewer severe events, and an alternative to hospital when they happen.

By producing data that resonated with the clinical community for their patient cohorts, then sharing the results with that community could provoke change. If there is data on workload, patient outcome, and opportunities to affect these things – then it data driven service change might be effected as part of a quality improvement cycle.

METHODS:

DEFINING A COPD ADMISSION

COPD admissions often present to the Accident and Emergency Department (AED) via 999 calls in an acutely breathless state. At this stage, staff may not know the diagnosis since many conditions cause breathlessness, and thus coders may record the first diagnosis the symptom "breathlessness" – ICD code R44.

The patient may go for an x-ray, and if there is a patch of shadowing, clinicians may record that as a localised pneumonia and so 'Pneumonia (J18)' appears as the second code. The full diagnosis may only appear later after admission and so the J40-J44 codes that usually describe COPD appear in third place. For the clinician, this is a COPD admission. If the patient was known to the admitting clinician they might have recorded "known COPD patient with worse breathlessness", which would have resulted in a COPD code being first in the coded list.

This coding dilemma cannot be solved by looking for COPD code in any position because in many cases the COPD will be a co-morbidity. For example, a COPD patient could be admitted with a heart attack, a diabetes crisis, or any other medical problem where the COPD is incidental to the admission.

We built on earlier work presented to the British Thoracic Society (in 2013) in which the principles as to what codes should (and should not) be included to describe a case that is most likely to have been admitted for COPD, ie. a professionally-reviewed list. We constructed an algorithm on the basis of:

a) A medical admission (ie. to a medical speciality)
b) An emergency (ie. not elective or day case)
c) COPD in the first diagnostic coding position and
d) COPD in positions 2 and 3 as long as a set list of codes appears in position 1

We recorded how the patient had arrived, where they had come from, the speciality of admission, the demographics, the diagnosis, the length of stay and their outcome, including where they were discharged to. We examined their individual history to record which patients were already known through previous admissions or visits to ED; and the readmission rate or reattendance rate after the admission. Death in hospital was noted but the data set does not record the ONS record of death when it happened post-discharge.

MAPPING

For each admission, we know the Lower Super Output Area (LSOA) where the admissions came from. This allows the sources of admissions to be mapped.

In addition, we calculated age and gender-adjusted admission rates to allow comparisons between areas based on the characteristics of their population.

Geospatial statistical techniques were used to identify clusters of high admission rates, i.e. hotspots.

CATCHMENTS

The NWC includes 19 CCGs served by 12 hospital trusts that admit adult medical emergencies. Our reports were therefore prepared at trust level so it was necessary to define the catchment populations.

The LSOA admission rates can then be compared with similar values calculated per General Practice and the two can be mapped together so that it is possible to relate the primary care services vs the admission rates.

However, there is no data available to us on the local social service provision, on the location of drop-in services, or the community nursing services.

DEFINITION OF A CONSISTENT CONTROL GROUP

Finally, based on the well-established fact that there are big differences in emergency admission rates between those well off and those who are economically deprived, we set up a comparator that could be used to compare trust catchments across the area.

The "Index of Multiple Deprivation" (IMD) ranks all LSOAs in England. CHC defined quintile boundaries from the national list and applied those to the NWC. This "national middle quintile" group are generally better off than the average for our NW catchments but create a control group that is comparable when comparing areas with it. That is, comparing health without a bias from deprivation and using this selection to also compare with the hotspots.

RESULTS:

IDENTIFYING COPD ADMISSIONS

Identifying the COPD cohort by using the CHC algorithm results in 45% more admissions being identified across the NWC than if only COPD in first coding position had been used and this figure varies between 30-60% for individual trust catchments.

These additional cases are quite different in three ways:

- The first coding position only group are younger (70.5 *vs.* 73.3) and more likely to be readmissions, suggesting a lower threshold of admission
- Cases identified using coding position only are **less severe** than those with identified with the algorithm (mortality rate 12.4% *vs.* 3.8%)

- Checking numbers with local clinicians confirms earlier work we conducted with the British Thoracic Society that this is a more realistic representation of clinical practice.

To miss out the most severe group means that a cohort needing the most intensive medical help are being overlooked and potentially undermines the viability of integration plans.

All the clinicians commenting on the reports felt this was a **more realistic description of their daily COPD experience** than the figures produced by various NHS bodies and thus a better starting point from which to plan/organise/commission services.

ADMISSIONS OVER TIME AND LOCALITY

- Rates of admission rise sharply with increasing age in a non-linear manner – so any statistical corrections should be performed with logistic (not linear) statistical models.
- Rates of admission per LSOA vary hugely (from 0.1 per thousand per annum to 36.5 per thousand per annum) and these differences become more marked when corrected for age which suggests that more focused services would have greater impact**.**
- The most deprived LSOAs tend to have fewer old people so resulting in higher rates per unit population when adjusted for their age profile.

The most deprived populations also have lower life expectancy and develop disease earlier in life – our data confirms that and shows the need to apply statistical control factors with more care than is routinely used. Risks of admission are the same for deprived and well-off populations with age.

- Overall numbers of COPD admissions continue to rise in line with total emergency medical admissions nationally
- Most (90%+) of COPD cases arrive via a 999 ambulance or directly from the GP
- Weekend admission patterns differ: there are fewer from the GP and fewer absolute numbers on Saturdays and Sundays. 999 admissions have a higher mortality than those sent in via the GP and the lack of GP referrals at the weekend helps explain why in-hospital mortality rates are higher at weekends as they will be arriving by ambulance.
- One-third of NWC LSOAs are in the most deprived in the country, and they account for one-half of all the COPD admissions in the region.

DETECTING HOTSPOTS OF ADMISSION ACTIVITY

In each hospital catchment there are hotspots, typically covering five to seven LSOAs, which stand out as clusters of high admissions – typically these are also the most deprived localities within the catchment.

These “hotspots”:

- Are typically served by four or five GP practices who also serve an area of lower admission rates around the hotspot. Nevertheless, these practices have age/sex-adjusted COPD admission rates significantly above the local mean.
- Are areas of extreme deprivation and have three to four times as many COPD admissions as LSOAs within the catchment, who fit the “national middle quintile” IMD group definition.
- Compare the middle quintiles across the catchments showed that there are differences in admission levels that are still very obvious indicating that there are more reasons to explore than deprivation alone (from 3.0 to 5.3 per 1000 population).
- Demonstrate the lower age of admission from “hotspots” which is compatible with people getting disease earlier in life. The lower in-hospital mortality - more than can be explained on age grounds, suggests a lower threshold for admission.
- Give a possible explanation that a breathless person who is too breathlessness to make their own way to a walk-in centre or GP surgery, does not own a car andis unable to call on a relative to drive them will call 999.

ACTIONS AND CHALLENGES GENERATED BY THE CHC REPORTS

- CHC created 12 reports (one for each trust) based on the data, and circulated them to the respiratory physicians, the medical director and the relevant CCG leads. Each was accompanied by an explanation of how the data had been arrived at, why it differed from other data they were likely to see, and gave suggestions for further actions to improve services.
- Feedback was generally supportive and there was interest in the report being more likely to correctly represent the clinical reality.
- Four CCGs expressed interest and two meetings were arranged. In both CCGs, clinical leadership was enthusiastic to explore the data further.
- In the first CCG, initial meetings with the CCG leadership led to a further presentation to the public health strategy group (including primary, secondary care and management) at which there was considerable enthusiasm to try and act. The CHC team met their

leaders for IT/local data and a team from the practices in the hotspot area. However, due to conflicting demands on time, further action was not taken and further meetings with primary care never happened despite repeated requests. The local IT leadership were keen to work with us toward implementing some of the data locally and potentially working to link with five primary care practices data. However without the active support of all primary care practices, no action was possible. Potentially in these five practices additional activity could improve reviews of their COPD patients and attempt to pre-empt the need for admissions..

- We had two meetings with the second CCG, one of which included leadership from primary and secondary care. However, the secondary care leader obtained a post outside the locality and the local drive was lost. No further meetings took place once the clinical leader had departed.
- Follow up data reports adding more detail and updated to the later time point were sent out 12 months after the original reports. These showed that the same problems and same opportunities still existed. A Physician Associate scheme instigated in Cheshire and Merseyside in June 2019 and focussing on working with GP practices in the region will indicate improvements in the final report which will be prepared in April 2020.
- Further reports may look different due to the impact of the Corona Virus

UNDERSTANDING DATA

In parallel to CHC's work there were two other local initiatives:

a) RightCare produced reports for the area and promoted them in local meetings. These used a different denominator for admissions than CHC data. b) the Health Care Partnership in Cheshire and Merseyside identified a lead physician to co-ordinate eight physician associates to support and improve local COPD care particularly in the community.

The **Getting It Right First Time (GIRFT) initiative** (in parallel with RightCare) has adopted our COPD admission definition and is making use of it in their work with trusts and CCGs.

CHC has taken a "clinical view" of the COPD admission and believe that our denominator is more likely to be reflective of the picture as encountered by staff in the front line. To be beneficial for local planning national bodies could build on CHC work in the future. CHC data may be an opportunity for future quality improvement initiatives which may want to view data at a local level.

WORKING WITH BUSINESS INFORMATICS TEAMS?

There was an intention at the outset of CHC that the local Business Intelligence (BI) community would, , be actively involved in producing data that monitored and advised local care delivery.

However, after a number of engagement activities it is evident there is limited time for them to engage on any activities other than those already delegated for them. Opportunities to drive quality and performance are set elsewhere in the system.

DISCUSSION:

CHC has shown that is possible to create reports describing the COPD admission patterns with numbers that:

a) are a more clinically realistic description of the local situation and therefore a better starting point from which to have local discussions
b) are shared with clinicians **in the front line** – most NHS data does not get to clinicians but stops with managers who are one step away from that front line
c) provide an added value in knowing where patients are located to both understand their issues and focus service delivery to meet those issues.

CHC has also shown that producing reports alone is not enough. There needs to be a concerted effort to create actions and achieve change through a multi-disciplinary approach across primary and secondary care.

COPD ALGORITHM

This will be written up and reported upon in more detail, and potentially its clinical definitions could be applied to **all** NHS analyses. The algorithm is currently stored on GITHUB and is available for adoption by BI teams across the region.

Unless data reflects realistic clinical practice, reports are likely to be either sidelined.

There are several definitions of COPD based on the HES data set that are in current NHS usage and so for GIRFT to join up with our system is a positive step, which will have a country-wide effect.

There is a need to create and agree a wider national view as to how to analyse NHS data.

OBSTACLES

The biggest obstacle to the CHC programme was in getting started. Getting permission to access and use anonymised linked data from NHS Digital took 18 months.

There is a need to create a more streamlined and effective access approach that maintains the security and confidentiality of the data but also does not waste time within projects funded by the taxpayer.

Getting the TRE to work well also took time and energy. There were issues for everyone in the process and much learning has gone into creating a TRE that is now genuinely fit for purpose. Data are now held securely here and authorised staff can access and work on the data with access to all the statistical and other tools they need.

There has been uncertainty by both the NHS and Universities about the legal and other regulatory processes that govern data use. Errors that might be referred for fines from the Information Commissioners Office invokes risk averseness. This is a national issue which is being addressed.

CHALLENGES WITH INVOLVEMENT OF THE NHS

There are three aspects to this – data staff, front line staff, and managers. CHC has approached all three groups and achieved expressions of interest and enthusiasm but has been unable to take those further because of resourses required to drive it forward.

Data staff: When analyses are done in universities and arrive via the CCGs in a trust, the local BI teams have not necessarily been included and may not invited to be involved. When CHC staff met with them at local events, many expressed an enthusiasm to be involved in helping to improve local services with their clinical staff, however due to demands on their time, this may not always be possible.

Front-line Staff: the NHS clinicians are also busy doing the 'day-job' and many are not willing to get involved in data – partly because they have found much of the data difficult to interpret and partly because the effort of trying to secure change is very time-consuming and that time is not available in working hours. Clinicians cannot attend meetings that occur when they have fixed clinical delivery sessions, however there are clinical staff who can see how things could be improved and their input to these processes are vital.

Managers: need to balance the demands to meet targets with the ability to use data to form ideas that can better structure and deliver services in discussion with front-line teams.

There are competing demands with existing targets and also issues which span organisations and need to include commissioners and community teams. Without the key players being fully involved, any data reports may not be fully utilised.

OPPORTUNITIES

The working TRE and the data reports for trusts create a number of opportunities for continuing the work, along with the funding of the Civic Data Trust in Liverpool, a respiratory strategy developed by the Innovation Agency (Academic Health Science Network for the North West Coast) the ongoing Physicians Associate Scheme in Cheshire and Merseyside and the Lancashire and South Cumbria Respiratory Strategy.

SUS data can be made available about three months after the period they describe – the point at which data submitted from trusts is considered to be "fixed", ie. unlikely to be edited or changed. That means that analyses could be with the trusts within three months of the period described, i.e. at a point when staff who delivered care can relate to the reports.

Specifically the following may also be possible:

Focus at a locality level

By investing where the need is greatest then the likelihood of significantly reduced admission numbers is also greatest. It is worth noting that in some of the LSOAs there are very few COPD admissions – so a negligible opportunity to save.

The hotspots can be identified and the staff serving those areas can be involved. The GP practices, the community staff and the hospital outreach could be brought together to consider how to tackle the COPD admission issues. For this sort of integrated care to happen there needs to be a dialogue between hospital outreach sharing their expertise and the locality teams managing the patients at home.

It will be useful to consider what services are available for people with COPD in an exacerbation. Increased breathlessness makes it hard for them to attend a walk-in centre so can the NHS go to them? Can short-term social support be available to tide over the crisis? Can an individual plan be in place for those at increased risk of admission? It is much easier to establish in a locality that across a whole district.

Make use of hospital systems to identify at-risk individuals

To run the algorithms inside each trust on the trust's own data in real-time and to generate alerts to help clinicians, e.g. "this is a patient from the COPD hotspot – suggest contact

COPD outreach team directly". This would begin the process of helping the patient back to activity in their community on day one of the admission rather, than waiting several days for the respiratory team to be involved. Getting patients to the right team can save days and can trigger local actions to help patients cope in the community in spite of their disease. Alternatively direct discharge to the local team may be possible with the appropriate short-term support. Note that many COPD patients would rather not be admitted if there is an appropriately supported alternative (reports noted from BreatheEasy over many years of national guidelines and audit).

Patient Self-Management

There are a range of Apps and other support devices which can help people with COPD to self-manage and linking these to a data system across the locality may effective. Putting support into the person's control, rather than having to rely on visits from professionals may be a significant opportunity, particularly for those who have early stages of COPD. Linking such Apps electronically to the data resources (with patient consent) offers a means toward more personal care albeit delivered via electronic means.

FUTURE PLANS/SUSTAINABILITY:

Aspects of the healthcare data laboratory at the University of Liverpool will be absorbed into the work of the Liverpool Health Partners and the Mersey data Co-operative – both organisations that bring together health and academic partners to work with the local populace for better health outcomes.

The Liverpool Civic Data Trust will provide significant opportunities to look at multi-morbidity and make use of the algorithms that have been developed

The algorithms are available on Git-hub and will be written up in academic reports to both ensure they are in the public domain but also to demonstrate their utility.

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