Eye health in Lancashire and South Cumbria

A joint strategic needs assessment

This report presents the key findings and intelligence from this multi-agency project, along with the priority issues and some strategic recommendations for action to improve eye health and prevent sight loss in the Lancashire and South Cumbria area.

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Foreword

Sight loss and poor eye health are a major cause of disability and poor quality of life. They have far-reaching effects on individuals, communities, the health and care system, and the wider economy.

Sight loss disproportionately affects older people, and our ageing population means that poor eye health and sight loss are increasing. But through early identification and effective treatment about fifty per cent of sight loss is preventable (RNIB, 2009).

For those already affected, good quality accessible services, information and support can help people make the most of the sight they have and enable them to live happier, healthier, more fulfilling lives.

Joint working is key to improving outcomes.

Organisations from all sectors across Lancashire and South Cumbria need to work together, making the best use of collective resources in order to make a real impact. This joint strategic needs assessment marks the beginning of that journey.

J. en



CC Shaun
Turner
Cabinet Member
for Health and
Wellbeing and
Chair of the
Lancashire Health
and Wellbeing
Board.

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Introduction

Background

The England Vision Strategy is part of Vision UK's country-led approach and in 2018 their six priorities were updated to form the foundations of change from 2018-2021:

- Prevention
- Commissioning
- Services
- Independence
- Self-determination
- Inclusion

Locally, there was a recognised need for intelligence to support a better understanding of eye health and sight loss in Lancashire and South Cumbria and in March 2018, a proposal for a thematic JSNA for eye health was approved by the Lancashire Health and Wellbeing Board.

Stakeholders from more than 20 organisations and from all sectors across Lancashire and South Cumbria came together in June 2018 to give their input into the scope and goals for the project, and the project team, led by Stuart Clayton – CEO, Galloway's Society for the Blind, initiated the work.

This report presents the key findings and intelligence from this multi-agency project, along with the priority issues and some strategic recommendations for action to improve eye health and prevent sight loss in the Lancashire and South Cumbria area. In addition, there is a wealth of data and intelligence relating to eye health on the Lancashire Insight web pages – the online home of the Lancashire JSNA. To access all the related material please visit:

www.lancashire.gov.uk/lancashire-insight.

Scope of this project

This JSNA project was carried out across the Lancashire and South Cumbria Integrated Care System (ICS) area. This covers the 12 county districts of Lancashire plus Blackburn with Darwen, Blackpool, Barrow-in-Furness, South Lakeland and parts of Copeland and Craven (see appendix A). This area has a population of approximately 1.7 million.

In order to make the project manageable, after the initial scoping exercise the decision was taken to focus on the adult population aged 18 and over. However, to facilitate a preventative approach, it was essential to make reference to how services and systems relating to children and young people could be improved.

Definitions

The term Lancashire-12 refers to the geographic area encompassing the 12 county districts of Lancashire. Lancashire-14 represents the wider Lancashire area encompassing the 12 county districts of Lancashire plus the two unitary authorities of Blackpool and Blackburn with Darwen. For more information about the geographies used in the Lancashire JSNA please visit our geographies page on Lancashire Insight at: https://www.lancashire.gov.uk/lancashire-insight/geographies-of-lancashire/

The following definitions are taken from The Criteria for Certification (RNIB, 2019).

Visual acuity is described as your central vision, the vision you use to see detail. **Visual field** is described as how much you can see around the edge of your vision, while looking straight ahead.

To be certified as **sight impaired** (partially sighted), a person's sight has to fall into one of the following categories, while wearing any glasses or contact lenses needed:

- visual acuity of 3/60 to 6/60 with a full field of vision;
- visual acuity of up to 6/24 with a moderate reduction in field of vision or with a central part of vision that is cloudy or blurry; or
- visual acuity of 6/18 or even better if a large part of the field of vision, for example, half is missing or a lot of a peripheral vision is missing.

Generally, to be certified as **severely sight impaired** (blind), a person's sight has to fall into one of the following categories, while wearing any glasses or contact lenses needed:

- visual acuity of less than 3/60 with a full visual field;
- visual acuity between 3/60 and 6/60 with a severe reduction in the field of vision such as tunnel vision; or

 visual acuity of 6/60 or above but with a greatly reduced field of vision, especially if a lot of sight is missing in the lower part of the field.

A **certificate of visual impairment (CVI)** will be issued by an ophthalmologist if they determine that a patient is sight impaired or severely sight impaired. A copy of this online certificate is sent to the patient, their GP and the local authority.

Upon receipt of the certificate, the local authority social services department contacts the patient to ask whether they would like to be added to its **register of visually impaired people**. If a person chooses to join the register, they will be contacted again by social services to arrange for them to be assessed to see what support can be provided to help them maintain their independence. Being on the register is not compulsory but can entitle individuals to certain benefits such as Personal Independence Payment – a tax-free government benefit to help with disability-related costs, TV licence fee reduction and parking concessions.

Impact

Sight loss affects more than two million people in the UK (Pezzullo, Streatfeild, Simkiss, & Shickle, 2016). Sight loss and poor eye health have far-reaching impacts on individuals, communities, health and care services and the wider economy.

On an individual level, people with sight loss are more likely to struggle financially, with only one in four registered blind or partially sighted people of working age in employment. People with sight loss often have lower wellbeing and a feeling of isolation, which can lead to more significant mental health issues if left unchecked. Access to travel and transport can be a significant difficulty for people with sight loss and could be a barrier to them getting out into the community. This could impact on their ability to work, enjoy leisure activities, visit friends and family and attend medical appointments. Some people with sight loss rely on care to support them in their day to day life. This care can often be informal and unpaid and could impact the wellbeing of caregivers.

The estimated economic cost of eye health and sight loss in the UK is £28 billion per year, which includes direct costs linked to prevention and healthcare, and indirect costs such as unemployment and informal care (RNIB, 2018). The project group submitted a Freedom of Information request (FOI) to hospital trusts across

the Lancashire and South Cumbria ICS area. This revealed the cost of missed appointments across ophthalmology departments to be over £2.5 million in 2017/18. Attending medical appointments can be more difficult for people affected by sight loss, and issues such as the formatting of appointment letters, transport, and hospital signage can hamper a person's ability to attend.

Key findings

Prevalence

There were an estimated 61,620 people of all ages in the Lancashire and South Cumbria ICS area living with sight loss in 2018. This represents around 3.6% of the population.

By 2030 this is expected to rise to 76,410 – an increase of 24% over 12 years.

53,390 people (87% of those with any sight loss) were estimated to have mild or moderate sight loss (partial sight) and 8,220 were estimated to have severe sight loss (blindness).¹

Only 11,965 people were registered as sight impaired with Lancashire County Council, Cumbria County Council, Blackburn-with-Darwen Borough Council or Blackpool Council in 2017^2 .

A total of 1,070 Certificates of Visual Impairment (CVI) were issued in Lancashire-14 and Cumbria during $2016/17.^3$

The projected increase in the number of people with sight loss across the ICS is largely, but not entirely due to an increase in the older population. Projected increases in risk factors such as diabetes also come into play, so the

Key points

More than 60,000 people are living with sight loss across the ICS. This figure is expected to rise.

Prevalence is increasing due to the ageing population and increases in the prevalence of key risk factors.

More than 60 0

¹ Figures do not sum due to rounding.

² Data were unavailable for the other authorities.

³ This includes the whole of Cumbria, not just those parts within the ICS area, and excludes Craven.

Key points

Only a small proportion of eligible individuals are registered as sight impaired.

Improvements in data management and sharing practices will facilitate the production of better intelligence to support commissioning.

continued drive to increase diabetes diagnosis rates will play a part in the prevention of sight loss.

It is apparent that not all people eligible to be registered as sight impaired with the local authority are indeed registered. Individuals are not always being encouraged to register with the local authority and therefore are not accessing the support on offer to them. This includes support from rehabilitation officers for visual impairment (ROVIs).

Data

Data issues hampered any detailed analysis of sight loss registers. Local authorities are required to submit this data to the government every few years but registers need better maintenance to ensure that records are removed when appropriate. This is an area for potential improvement.

Some health data were not available for the ICS area but plans are in place to improve the availability of data within this geography.

Risk factors

Several health conditions are known to be risk factors for sight loss. These include diabetes, for which obesity is a risk factor, glaucoma, macular degeneration, cataract and rheumatoid arthritis.

Diabetes and related conditions

Recorded **diabetes** prevalence stood at **7.2%** in 2017/18 across the ICS area. This was significantly higher than the England prevalence of 5.8% and represents just over 103,000 individuals aged 17 and over. However, the estimated prevalence of recorded and unrecorded

diabetes was 9.0% in 2017, indicating that there are many undiagnosed cases.

Across the north west of England the uptake of diabetic eye screening was significantly lower than in England as a whole in 2017/18 at just 79.4% compared to 82.7%. Prevalence of diabetic eye disease across Lancashire-14 and Cumbria was 3.3 per 100,000 in 2016/17. This was statistically similar to the England prevalence rate of 3.1 per 100,000. In Cumbria this rate is decreasing over time (getting better).

In 2017/18, 10.5% of adults in Lancashire and South

Cumbria ICS area were **Obese** according to general practice records. This was significantly higher than the England prevalence of 9.8% and represents a total of almost 150,000 individuals aged 18 and over. Recorded prevalence of adult obesity in the area has remained similar over recent years.

Rheumatoid arthritis

Prevalence of **rheumatoid arthritis** in Lancashire and South Cumbria ICS area has remained at 0.8% over the last few years and this rate is now significantly higher in statistical terms when compared to the England prevalence of 0.7%.

Cataract

In 2018 there were an estimated 19,540 people living with cataracts in the ICS area. This is an estimate and cannot be compared to the national value.

Key points

10.5% of adults are obese putting them at risk of diabetes.

7.2% of adults have diabetes, putting them at risk of eye diseases and sight impairment.

Key points

Rheumatoid arthritis prevalence is higher than the national rate.

Glaucoma is on the rise in Lancashire-12.

Glaucoma

In 2016/17 the Lancashire-14 and Cumbria prevalence of **glaucoma** (adults aged 40 and over) was **14.7** per 100,000. This was statistically similar to the England prevalence of 13.1 per 100,000. In Lancashire-12 this prevalence rate is increasing (getting worse) over time.

Age-related macular degeneration (AMD)

The 2016/17 prevalence of AMD (among adults aged 65 and over) across the Lancashire-14 and Cumbria area was 116.7 per 100,000. This was statistically similar to the England rate of 111.3 per 100,000. In Cumbria this rate is decreasing (getting better) over time.

Prevention and protection

Some people with known risk factors may already have some level of sight loss, others will not. There are many opportunities to intervene in order to protect people's sight and stop existing conditions worsening.

There are known discrepancies between estimated and recorded prevalence of diabetes both locally and nationally and there is an opportunity for continued awareness-raising and opportunistic testing to increase the diagnosis rate.

Ensuring that every effort is made to encourage and support people with diabetes to attend the regular retinal screening appointments they are eligible for will help protect this at-risk group.

In 2018 there were an estimated 3,580 falls across the ICS area directly attributable to visual impairment.

Information and advice

There is a variation in support available across Lancashire and South Cumbia to those who have sight loss.

It is clear that not all patients attending hospital ophthalmology appointments are given the opportunity to speak to an eye clinic liaison officer (ECLO). ECLOs are often the first person a patient will come into contact with following a diagnosis and play a key role in supporting patients in coming to terms with their condition. They can provide practical and emotional support and further information at a time that can be very uncertain for an individual.

"my ECLO helped me to understand my eye condition and the registration process"

"the ECLO provided advice and guidance on the statutory benefits I may be able to access"

In Lancashire and South Cumbria ICS the provision of ECLOs is not universal. It differs by hospital, and by day and time of appointment.

Services

This project has revealed that many patients are not attending appointments at eye clinics. In 2017/18, more than 22,000 first and follow-up appointments were missed across the ICS area (all ages). The financial costs of these missed appointments was in excess of £2.5 million, and potential health costs to

Key points

The financial cost of missed eye clinic appointments in 2017/18 was over £2.5 million.

There are many quick wins to improve attendance at eye clinics and prevent the deterioration of sight.

individuals could include the avoidable deterioration or loss of vision. These figures don't include cancelled clinics, an issue which also needs to be addressed.

There are many reasons why a person may not attend an appointment, but the evidence shows that a few relatively simple changes could make a big impact on reducing missed appointments.

"make hospital and council letters available in other formats so [I] don't have to rely on others"

Making sure appointment letters are sent out in a suitable format and in a timely manner, supported travel and accessible clinics would all help. The UK Ophthalmology Alliance and RNIB have put together a set of patient standards to increase support for eye clinic patients (UKOA; RNIB;, 2018).

Individuals have told us their views about local services and tend to agree that further information, access to practical support and guidance is mainly provided by local societies and other voluntary agencies, such as RNIB, Age UK and Citizens Advice and is not always forthcoming through the eye clinics.

"I feel I have had to find out about my sight loss myself"

"not enough time [at appointments] for things to be explained"

"registration process not really explained"

"did not get diagnosis quickly... if appointments more efficient would not have lost as much sight"

Quality of life

Our local case studies highlighted some of the things that are important to local people with sight impairment and the personal impact.

Rehabilitation officers for visual impairment (ROVIs) can support individuals to make the most of the sight they have to live a fulfilling life and to do and achieve all that they want to. As previously mentioned, it is important to ensure all eligible people are actively encouraged to register, if they wish to do so, with the local authority to receive this support. If a person with sight loss does not wish to register as blind, ROVIs and other social care teams may still be able to offer

"I try to be as self-sufficient as possible"

"potholes and pavements uneven and I have hurt my ankle and tripped which has knocked my confidence"

some support to meet their needs. The safe use of public spaces can be impeded by factors such as poor street lighting, 'shared spaces', excess street furniture (bins, railings, seats and signs for example) and poor pavement/road conditions. This can restrict people in being out and about in their local communities and can lead to increased isolation and reliance on others. The emphasis should be on the relevant local authorities to maintain a safe and uncluttered public realm for all people with accessibility issues.

"dark or low lights a barrier so [I] don't go out at night"

"some days I don't feel I can communicate with others"

"it is not always easy to get [training] courses in audio form"

"I am in the house a lot because of transport issues: surroundings can be a problem if confined or crowded e.g. shop aisles"

Priorities

The eye health stakeholder reference group came together in November 2018 to review the key findings from the JSNA analysis and to identify priorities for local improvement. Delegates worked in groups to discuss the key issues and give input from their own professional or personal perspective about what needs to be prioritised to ensure the best outcomes for the local population.

- Prevention and protection
- Information and advice
- Services
- Data
- Inequalities
- Quality of life

Prevention and protection received 87 votes, information and advice received 59 votes, there were 50 votes for services, 46 for data, 30 for inequalities and 27 for quality of life. The overall results reveal that prevention and protection was the highest priority issue. It was also felt that tackling the other issues would lead to a better quality of life and reductions in inequalities for people with sight loss.

What is already being done?

The NHS has committed to working with partners to ensure that children with learning disabilities, autism or both are given sight tests in special residential schools (NHS, 2019).

All children in mainstream education in Lancashire have a vision screening within the first year of school. This is an orthoptic-led service and any child failing the required vision standard are referred onward to their local hospital eye service.

Currently, some areas have a minor eye conditions scheme which allows patients to attend their local optometrist if they have symptoms of red eye, flashes and floaters and eye discomfort. This is in line with the national Systems and Assurance Framework for Eye health (SAFE) from the Clinical Council for Eye Health Commissioning (SAFE – Urgent and Emergency Care). This service is commissioned in Preston, Chorley and South Ribble, Blackburn with Darwen, East

Lancashire and the Morecambe Bay area.⁴ As this service is locally commissioned, it can present cross-border difficulties – a patient who receives an eye test at a practice in an area where it is commissioned can only be offered the service if they also live within that commissioning area.

Diabetic screening for all adults with diabetes is available throughout the ICS area. This is delivered virtually, whereby the patient attends their local clinic for fundus photography (image of the retina of both eyes). These images are then reviewed by a specialist to assess for evidence of diabetes in the eye and the potential risk of sight loss. If a specified degree of diabetic retinopathy is found, the patient is referred to their local hospital eye service for treatment or monitoring.

The NHS aims to reduce inequalities in diabetes and minimise the risk of complications through continued investment in supporting delivery across primary care (NHS, 2019). It will be developing and expanding the diabetes prevention programme to offer digital access from 2019 and enhance its support offer to people with diabetes including the expansion of structured education provision.

The <u>NHS Diabetes Prevention Programme digital stream</u> provides support, assistance and guidance around weight, physical activity and healthy eating to those at high risk of developing Type 2 diabetes through the use of wearable technology, apps, online peer groups and electronic goal setting and monitoring. Lancashire and South Cumbria ICS is one of eight areas nationally selected to pilot these digital interventions.

A pathway for patients who attend for a routine eye examination and are found to have high eye pressure (ocular hypertension) is available in the majority of areas in Lancashire and South Cumbria.⁵ This allows community optometrists to reassess and manage patients with ocular hypertension in the community until their condition is confirmed. This allows reductions in hospital outpatient appointments and allows patients to have care closer to home until a time when

⁴ At the time of the production of this report, this service was not confirmed in the other areas of Lancashire.

⁵ At the time of the production of this report, this service was not confirmed in West Lancashire.

onward referral is necessary. This is in line with national guidance (SAFE – Glaucoma). The degrees to which patients are managed by community optometrists is variable throughout Lancashire and South Cumbria.

Both pre- and post-operative cataract assessments are commissioned to align with national frameworks throughout Lancashire and South Cumbria (SAFE - Cataract). The pre-assessment ensures patients are eligible for and understand the risks of cataract surgery prior to referral to hospital. These are currently commissioned in Preston, Chorley, South Ribble, Blackburn with Darwen and the East Lancashire area.

Post-operative cataract assessments ensure patients can have their two- and sixweek follow-up assessments delivered in a community setting. This ensures care closer to home and reduces hospital capacity for routine cases. Post-operative cataract assessments are commissioned throughout most of Lancashire and South Cumbria.⁶

For patients who suffer with wet age-related macular degeneration (wet AMD), fast track pathways are commissioned throughout Lancashire and South Cumbria. This ensures patients with this condition have their needs met on an urgent basis, allowing treatment to be administered as soon as possible and maximising the efficiency of treatment (SAFE – AMD). However, because of capacity issues, there is variation in how soon a patient is seen and this can often exceed the NICE recommended two week timescale. This delay can have significant repercussions for the individual as the delay could mean their eye sight deteriorates and they are no longer suitable for treatment.

Recommendations

A literature review was carried out to identify best practice relating to the priority areas and this was amalgamated with suggestions made by the stakeholder reference group about how best to address the priority issues from a local perspective.

As the RNIB (n.d.) notes: "sight is incredibly precious and we live in an increasingly visual world. Levels of avoidable sight loss in the UK are

⁶ Ibid

unacceptably high. Around half of all sight loss is preventable". This emphasises the importance of investment in public health messaging, making eye services accessible to all, and making the link between the consequences of smoking, obesity, diabetes or high blood pressure and the increased risk of sight loss.

The UK Ophthalmology Alliance (UKOA) worked with RNIB to compile a set of patient standards for ophthalmology services (UKOA; RNIB;, 2018). They suggest: "there are many national standards covering patient focus and patient experience in healthcare, such as those from the National Institute for Health and Care Excellence (NICE), which should be respected for patients receiving ophthalmology services".

The thematic areas of prevention and person-centred services co-produced with the involvement of people affected by sight loss are critical factors in achieving improved eye health in Lancashire and South Cumbria. Another is improvements in accessibility of information for patients, their carers and parents, and visitors who have a disability or sensory loss. All organisations providing NHS care or publicly-funded adult social care services are required to adopt and implement the Accessible Information Standard (AIS) (NHS England, 2017). This is key to achieving equality for people living with sight loss.

Many of the recommendations below are cross-cutting and apply to more than one priority topic.

- Partners from education, children's services, health and public health to work together with sight advice centres to deliver information and training about eye health in schools.
- NHS and public health teams to expand existing health checks to include eye health.
- Health and social care teams to plan ahead to ensure information about individual eye health conditions or risk factors are passed on when children transition to adults' services.
- Deliver campaigns to raise awareness about eye health and sight loss, taking advantage of opportunities such as National Eye Health Week to raise the profile of the issues. Evidence suggests that targeted campaigns for at-risk groups can reduce inequalities, and that such campaigns should use media channels suitable to the sub-population of interest and feature

role models, examples and cultural signifiers appropriate to the intended audience (Baker & Murdoch, 2004; 2008; Cross, Shah, Bativala, & Spurgeon, 2005; Thornton, et al., 2005; Wormald, Basauri, Wright, & Evans, 1994).

- Clinicians to introduce awareness sessions in eye clinics to inform patients about risk factors, symptoms and services.
- Local politicians to lobby central government to introduce regulations requiring all drivers to have regular eye sight tests.
- Partners from Lancashire and South Cumbria ICS to develop a single online source for information and advice about everything from aids and adaptations, to sources of financial and emotional support and ensure there is a single point of contact for direct help and advice.
- All partners to work together to ensure opportunities for intervention are maximised. For example, giving out leaflets or information at blood pressure monitoring sessions.
- Establish effective training courses to ensure health and local authority professionals are well informed about eye health issues.
- Seek to secure sustainable NHS funding to ensure that every eye clinic has full-time ECLO provision, thus removing reliance on voluntary sector funding. (Clinical Council for Eye Health Commissioning, 2017; The Royal College of Ophthalmologists, 2019; UKOA; RNIB;, 2018).
- Review hospital administration systems to ensure appointment information is accessible across all departments.
- Conduct an audit of health services' and local authorities' accessibility policies.
- Ensure that staff have appropriate "people skills" when conducting appointments with visual impaired people. A sensitive and helpful approach is important to patients.
- Improve the accessibility of health services where necessary. This will
 help reduce 'did not attends', improve the health of people with sight loss
 and reduce some of the inequalities they experience.
- Provide multidisciplinary low vision clinics across the ICS, which provide
 patients with a chance to see an optical practitioner, a ROVI and a
 representative from the voluntary sector in a single setting.
- Target waiting lists for fast-tracked appointments.
- Introduce a national pathway of accepted standards (UKOA; RNIB;, 2018).

- Work together to secure funding and resources.
- The national rollout of the <u>NHS app</u> will enable patients to update their data sharing preferences from their computer or smartphone. This opportunity for data sharing should be maximised through education about the benefits of allowing data to be shared for care purposes.
- Continue to use intelligence from the Lancashire JSNA and other sources to inform service provision and influence decisions around eye health.
- Local authorities to lead on the simplification and transparency of the registration process, in collaboration with relevant partners.
- All partners to increase the provision and quality of information and advice.
- Implement the SAFE Framework (Clinical Council for Eye Health Commissioning, 2018), which provides the basis for commissioners, provider organisations and clinicians to adopt a high level, strategic, systems-based approach for the planning, provision and commissioning of eye health and care services, covering whole pathways and operating across traditional service footprints.
- Ensure services which are commissioned from national frameworks (SAFE), (Clinical Council for Eye Health Commissioning, 2018) are available across the whole area to reduce inequalities.
- Minimise cross-border issues in commissioned services.
- Produce a SMART⁷ action plan that references, where applicable, the indicators included in the SAFE framework and seek support for the establishment of an Eye Health Quality Board for the ICS area.
- Implement the locally deliverable recommendations from the "See the light" report (All-Party Parliamentary Group on Eye Health and Visual Impairment, 2018) to minimise the impact of cancelled eye clinics.
- Conduct service mapping across the eye health and sight-loss pathway to identify gaps in current and future provision and capacity.
- Produce a pathway-mapping template similar to that produced by London local eye health network (LEHN) and distribute to stakeholders such as Local Optometric Committees. (See downloads at https://www.lancashire.gov.uk/lancashire-insight/health-and-care/disability/physical-disability-in-adults/)

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⁷ See, for example: https://www.projectsmart.co.uk/smart-goals.php

 Share and learn from the Surrey cost-avoidance case study for rehabilitation services to demonstrate the impact and value of rehabilitation services (OPM Group, 2017).

By implementing the recommendations for the key issues, quality of life will be improved for people with a visual impairment and the prevention agenda will reduce the number of people who experience unnecessary sight loss.

"now attend blind society, great help"

"Barrow VSC gave emotional support and help in understanding condition"

"have been helped by Galloway's physically and mentally"

"talk helped me to understand what was happening"

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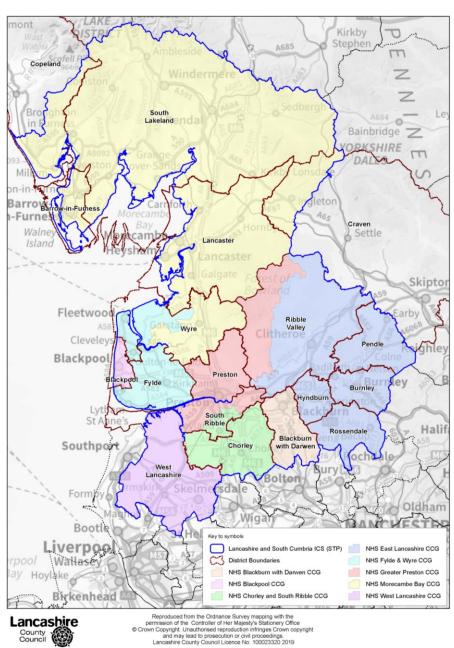
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Appendices

Appendix A – map of the Lancashire and South Cumbria Integrated Care System (ICS) area.

The map shows the geographical boundaries of the ICS and the local authority districts and clinical commissioning group areas within it. Several areas overlap.





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