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1. Executive Summary

The vision - to seize a once in a generation opportunity to ensure that Humber and North Yorkshire is the central driver for improved health, care, and wellbeing outcomes for the population through data driven integrated and redefined service delivery. Our aim is to revolutionise health and care in Humber and North Yorkshire through the strategic application of data science alongside local professional wisdom and voice of people in our communities – ensuring Humber and North Yorkshire is the heart of leading integrated service delivery across Yorkshire. This will begin with a focus on children and young people, enhancing service delivery and ultimately driving value across the whole life course and narrowing the gap in healthy life expectancy.

The problem - More than 200,000 of the 1.7 million people who live in Humber and North Yorkshire are living in poverty, with more than 60,000 children living in low-income families. More than 2,400 people each year die from causes considered preventable. Within Humber and North Yorkshire there is a considerable gap in healthy life expectancy (up to 15 years) between those from the most and least deprived communities in the area. The evidence is clear - our inability to share information acts as a major barrier to planning and delivering integrated care and driving forward the health, care, and wellbeing outcomes needed by our population.

The offer – We propose the creation of a Humber and North Yorkshire Integrated Data Engine for Analytics (HNY IDEA) centre that connects academic expertise with the ICP. HNY IDEA would oversee the creation of *'Connected HNY'* – a database capable of providing the data insights necessary to drive efficiency in integrated public service delivery and improve the health of the population. In parallel, the IDEA would develop *HNY Insights* as a platform that allows practitioners to share information efficiently and securely.

The recommendations - Our recommendations will help ensure this initiative will not only improves service delivery but also positions HNY as a leader in the use of connected data for public service enhancement.

- Create a HNY Integrated Data Engine for Analytics (IDEA) centre
- Establish a 'Connected Humber and North Yorkshire' database hosted within the NHSE Yorkshire Secure Data Environment (SDE)
- Focus initially on data applications involving children and young people
- Form an 'oversight and scrutiny' group containing national stakeholders
- Prioritise linking 'health' records with education records from the Department for Education in the first phase of work
- Adopt a place based level approach (based on Bradford's Act Locally programme) that brings the relevant stakeholders (health and education etc) together with communities to adopt data driven solutions to specified problems

Need for action - Compelling evidence has been provided (e.g., the [Child of the North report](#)) supporting the moral, ethical and economic imperative of using data more

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effectively to address health inequalities. A fundamental problem restricting integrated care is the inability of practitioners to share and integrate information across organisations. At a national level the future projections show further worsening of current trends in health and wellbeing with wider societal factors having profound impacts on our children and young people.

The impact - enhancing integrated places leading to new/improved cross sector collaboration and partnerships, enabling them to plan and invest together for long-term population gain based on a mutually inclusive return on investment model. Creating the opportunity for professionals from different sectors to work in harmony, using the same data to transform the life chances of our most disadvantaged families, improving the health, care and wellbeing outcomes of whole communities and developing long-term benefits and sustainable gains regarding turning the dial on health inequalities in Humber and North Yorkshire's most deprived wards.

Learning from Bradford - Bradford have built and tested the first 'Integrated Data Engine for Analytics' (IDEA) centre. The West Yorkshire IDEA centre directs and improves the design, delivery, and evaluation of public services (with a current focus on autism and 'early help'). The creation of a HNY IDEA network would build on the work of Bradford and transform policymakers' understanding of demand 'on the ground', facilitate its ability to predict need and provide data tools for designing and evaluating the impact of policies. Bradford has shown the power of connecting routine administrative records, including health, social and educational data, through both the Born in Bradford project and the Connected Bradford database. The evidence is clear that the IDEA centre concept is functional and effective in Bradford and there is a need to expand this further across Yorkshire in order to create integrated service provision and improve the health and wellbeing of a whole population.

Assets and partnerships available – The Connected Bradford team are offering their support to HNY. Importantly, the team are leading a 'Secure Data Environment' (SDE) initiative for Yorkshire which could support the creation of *Connected HNY*. The research-intensive universities across Yorkshire and the North of England (via the N8's Child of The North initiative) are able and willing to support HNY ICB, and the Alan Turing Institute have offered support through their 'Digital Twins' programme.

Test case implementation for Connected HNY – We propose that the HNY IDEA takes advantage of existing work across HNY that has created a cohort of families with linked datasets. BaBi uses an active consent process that enables identifiable, routine data from multiple sources to be linked to improve the health and wellbeing of families. Thus, it provides an excellent opportunity to engage with the community and 'prove the principle' of connected data for improved health outcomes.

Test case implementation for Connected HNY - We propose that the HNY IDEA takes advantage of existing work in Bradford which will immediately allow data driven place-based approaches to be adopted within HNY. Bradford have developed an electronic tool (the Electronic Developmental Support Tool, EDST) which addresses the current autism assessment and support crisis. The EDST provides a vehicle through which information can

be shared across health and education for a well-defined purpose. Most importantly, the EDST displays how health and education can come together to effectively support children and young people and displays the need for effective information sharing. This will help engage communities within the HNY IDEA from the outset but also lay the groundwork for the practical implementation of information sharing systems. It will also help address a major problem afflicting health and education with immediate effect.

The deliverable - HNY IDEA centre will join up approaches on the development of a common shared data infrastructure that can support and connect research, health improvement programmes, and underpin direct care across the region.

2. Humber and North Yorkshire

More than 200,000 of the 1.7 million people who live in Humber and North Yorkshire are living in poverty, with more than 60,000 children living in low-income families. More than 2,400 people each year die from causes considered preventable.

The healthy life expectancy – the number of years a person can expect to live in good health – is just 53.8 years for men in Hull, compared with 67.3 years for men in North Yorkshire. Within North Yorkshire there is a gap of 9.5 years between those from the most and least deprived communities.

For women in Humber and North Yorkshire, the number of years they can expect to live in good health is slightly higher than men but is just 56.4 years in North Lincolnshire, compared with 67.9 years in East Riding of Yorkshire. There is a gap between the most and least deprived of 11.2 years within East Riding.

The reasons behind these disparities are complex and multi-layered and are as individual as each of the 1.7 million people who live in our communities.

The ways to tackle these disparities are similarly complex and require organisations and communities to work together, to get creative and to have a clear goal to strive for.

The Humber and North Yorkshire Health and Care Partnership have set an ambitious strategy that is focused on narrowing the gap in healthy life expectancy by 2030 and increasing healthy life expectancy by five years by 2035, where we want every single person in our population of 1.7 million people to start life well, to live well, to age well and die well.

Futures Group

Humber and North Yorkshire Integrated Care Partnership took a ground-breaking decision in June 2023 to establish a Future Groups. The purpose of the Futures Group is to pursue partnership working that increases the capacity and effectiveness of the Integrated Care System in delivering on its long-term ambitions. The Futures Group goes beyond the existing health and care partnership (NHS, local authorities, patient voice, voluntary sector) and harnesses the capabilities of universities, colleges, the private sector (local, national and international) and health charities.

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The Futures Group is a ‘first mover’ (thought leader and innovator), generating multi-sector partnerships that considers the transformative change that would be required to have an impact on the health, care and wellbeing of the population in Humber and North Yorkshire. . The group opens up that bandwidth by focusing on the medium to long term only, and to not typically discuss matters which are likely to have impact within a three-year timeframe but preparing for the years beyond that.

Working across four main themes – research, workforce, technology, and population health – the futures approach of the Humber and North Yorkshire ICS it is hoped that it will be recognised nationally as a model for understanding and tackling the longer-term drivers which all too often manifest in short term pressures and reactive decision-making.

3. THE VISION

Our vision is to establish Humber and North Yorkshire as a national trailblazing site for the application of data science to drive improved health, care and wellbeing outcomes for the population through integrated and redefined public service delivery. Our mission is to place Humber and North Yorkshire at the heart of a community of practise across Yorkshire, strengthening partnerships, and pushing and pulling learning across the region. Specifically, we propose:

- Creating a **Connected Humber and North Yorkshire** database that will allow data insights to drive efficiencies in integrated public service delivery and improve population health and wellbeing.
- Developing **HNY Insights** as a platform that will allow practitioners to share information efficiently and securely.

Our goal is to empower communities to apply data science insights within their localities – creating data driven, place-based, whole system approaches to priorities identified by the community. These efforts will be underpinned with an ethical approach to community engagement and co-production – adopting methodologies tried and tested in Bradford.

4. RECOMMENDATIONS

- I. **Create a HNY Integrated Data Engine for Analytics (IDEA) centre.** The HNY IDEA centre will be a virtual group that builds on the Futures Group and brings together the necessary partners able and willing to deliver the Connected Humber and North Yorkshire vision of using applied data science to increase equity.
- II. **Establish a 'Connected Humber and North Yorkshire' database hosted in partnership with the NHSE Yorkshire Secure Data Environment (SDE).** The Connected Bradford team have confirmed their commitment to support deployment of the successful 'Connected Bradford' model. The Yorkshire SDE team have confirmed their desire to develop a system that is capable of hosting Connected HNY (and Connected Bradford). The creation of Connected HNY will ensure the region makes the most of its current data assets (e.g., the Patient Linked Data Sets within AXYM).
- III. **Focus initially on data applications involving children and young people.** A connected dataset provides a powerful resource that can help improve service delivery across multiple domains. But any long-term solution to addressing health inequity must focus on children and young people, and a single focus will help ensure there is a successful foundation for future expansion to other populations (e.g., older adults via electronic frailty indices etc).
- IV. **Establish HNY ICB as a national trailblazer for the use of connected data in improving service delivery.** The proposed HNY IDEA centre has national significance and could and should be used to promote the vision of the HNY ICB via opportunities such as the RCPCH annual conference. HNY will provide leadership in data science across the Yorkshire ICBs so that HNY can benefit from the advantages of a 'Connected Yorkshire' database. The ability to compare and contrast contextual factors across Yorkshire will allow more tailored health delivery and ultimately benefit the HNY and the Yorkshire population.
- V. **Form an 'oversight and scrutiny' group containing national stakeholders.** The group will provide assurance that the Connected HNY work is legal, ethical, and co-produced with communities. Senior colleagues (e.g., the previous Children's Commissioner and the President of the Royal College of Paediatrics and Child Health) have committed to sitting on such a group. The group will provide additional benefit in removing possible barriers to progress and facilitating national inward investment.
- VI. **Prioritise linking 'health' records with education records from the Department for Education in the first phase of work.** The cross-Whitehall 'Data Improvement Across Government' (DIAG) group have confirmed their interest in supporting the proposed work and helping HNY become a trailblazer in the use of connected data for improved public service delivery. DIAG will be able to help Connected HNY pull through a range of centrally held data for linkage but 'proving the principle' across health and education first provides an achievable goal that avoids the risk of overreach (and allows rapid implementation of an exemplar – see XII).

- VII. **Utilise support from academic partners to ensure analytical capacity to realise the potential of Connected HNY.** The N8+'s Child of The North consortium have promised academic support through their 'data asset' programme of work. This will allow HNY to call on expertise from across the eight research intensive universities in the North of England (including expertise in data science but also health economic modelling and a wide range of ethical and legal knowledge). This will involve working closely with the Alan Turing Institute in establishing and using Connected HNY. The Alan Turing Institute is the National centre for data analytics and 'artificial intelligence'. The Director of the urban analytical component of the ATI's 'digital twins' programme has confirmed the desire of the ATI to provide support to HNY.
- VIII. **Adopt a place-based approach based on Bradford's Act Locally programme that brings relevant stakeholders (health, police, and education etc) together with communities to adopt data driven solutions to specified problems.** There is a great opportunity to support the excellent place-based work happening across HNY with connected data insights. In turn, data driven place-based work will ensure community support for the HNY IDEA centre (via IX and X). Thus, the HNY IDEA centre has important synergies with the 'place level' public health management approach, links to health and wellbeing board strategies, and complements the focus on Integrated Neighbourhood Teams as a vehicle for improving health and reducing inequalities. This would ensure the HNY IDEA centre is a mechanism for obtaining scale and impact in population health improvement initiatives at the local level.
- IX. **Use Born and Bred in (BaBi) network data within the YSDE as a starting point for community engagement, service prioritisation, and demonstration of the power of linked data.** BaBi uses an active consent process that enables identifiable, routine data from multiple sources to be linked to improve the health and wellbeing of families. Thus, it provides an excellent opportunity to engage with the community and 'prove the principle' of connected data for improved health outcomes.
- X. **Use the 'Electronic Development Support Tool' (which allows the bidirectional sharing of information across health and education) developed in Bradford to address the autism crisis within identified localities (via a test and learn approach).** The single most important factor for success in creating Connected HNY and HNY Insights is community approval and practitioner endorsement. This requires a clear demonstration of the potential for a data driven approach to address a common problem. The crisis in autism assessment and support provides an outstanding exemplar as it cuts across health and education. Once more, a focus on a single issue ensures the project can be delivered without overreaching (or putting the system under pressure).

5. ALIGNMENT WITH EXISTING HNY ACTIVITY

HNY is ideally placed to act as a centre of innovation, establishing best practice and scalable solutions for data infrastructure, tooling, analysis, and research that can support and drive improvements in population health and reduce health inequalities.

The Humber and North Yorkshire system is already making strides in this area. ICB investment is enabling significant progress in the development of a linked data environment, bringing together health and care data from across the system. The opportunity afforded through the creation of the HNY IDEA centre is to build on existing work and ensure close alignment, at an early stage, with regional development in this space (particularly the regional Secure Environment ([SDE] programme).

The HNY IDEA centre will join up approaches on the development of a common shared data infrastructure that can support and connect research, health improvement programmes, and underpin direct care across the region.

HNY IDEA centre can add value to existing population health work at system and place

The HNY IDEA centre would generate impact through 'docking into' and offering tangible added value to existing place based and system wide population health programmes. The centre would provide opportunities for places to draw down on expert academic research capacity to bring new actionable insights and evidence to inform interventions and priorities for working with local communities.

There is a great opportunity is to integrate HNY IDEA as a key strand of the system wide approach to improving population health. The centre could help establish the right governance and prioritisation mechanisms, and effectively deploy academic expertise and resource against strategic population health priorities at place and system level.

HNY IDEA could also provide a framework for how HNY could draw on academic expertise for embedding evaluation, helping better measure the success of local initiatives including population health management projects across PCNs, Integrated Neighbourhood Teams (INTs) and GP practices.

At a system level, there is also potential for alignment with current thinking on the establishment of a 'Decision Support Unit' (DSU) approach for HNY, aimed at delivering strategic analytics work for the ICP Board with a focus on understanding and helping tackle our key system challenges in health and care. The addition of academic partner expertise within a DSU 'hub' of data science and analytics at a system level would significantly enhance HNY's capability in this area and would further strengthen links at system level on academic collaboration for improving population health.

6. THE NEED FOR ACTION

The evidence is clear: Our inability to share information acts as a major barrier to *planning* and *delivering* integrated care and driving health, care, and wellbeing outcomes for our population.

Public services are organised and delivered within specialist organisations (e.g., education, health, social care, and policing). Policies are developed within political structures that map to these organisations both *centrally* (e.g., DfE, DHSC, MoJ etc) and at a *local* level (e.g., multiple academy trusts, hospital trusts, local authorities, and regional policing authorities).

The fundamental problem is that the lives of families and individuals do not fall neatly within these **organisational silos**. This is why **'integrated care'** systems were created. Unfortunately, the planning of integrated care is thwarted through a lack of knowledge about how services intersect and interact within the lives of families. The delivery of **integrated care is hindered because practitioners can't share and integrate information** across organisations.

Health and social care in the United Kingdom are heading over a cliff. Alarms are screaming as the UK drops down the world rankings for infant mortality, and progress on improving healthy life expectancy stalls. Our public services are on their knees as the wellbeing of the population grows ever worse. The problems are multifaceted and apportioning blame is both impossible and unhelpful. These issues transcend party politics and require an 'All Party' approach if the UK is to reverse these worrying trends.

The evidence is conclusive - inequity is a root cause of many of the UK's ills. In 2010, Professor Michael Marmot showed that health inequalities caused premature deaths with a total annual loss of between 1.3 and 2.5 million years of life. Nevertheless, many people rode out the impact of rising inequity between 1980 and 2010 thanks to economic growth. Economic growth distracted the UK from heeding the health warnings and, ten years later, Marmot showed life expectancy had stalled or fallen (for the poorest women), healthy life expectancy had decreased, and the gap between affluent and disadvantaged areas had increased. But a global pandemic and subsequent economic stagnation means that the pain of inequity is no longer restricted to our disadvantaged communities. It is now being felt throughout the nation.

The problems are self-evident at the front line of our health system, with increasing waiting times for hospital appointments (particularly children) and a beleaguered workforce. Our front-line services are fighting fires that burn with an ever-increasing intensity. The fact that inequity is ultimately bad for (almost) everyone is demonstrated clearly by most of the population struggling to access timely healthcare – despite footing the hefty tax rises needed to prop up over-stretched public services. The situation is untenable and preventative medicine is required. The current scale of firefighting means that health practitioners have little capacity to administer the treatment and the depth of the problems means the past practice of relying on extra discretionary effort from frontline clinicians to solve the problems has long passed. Moreover, plausible solutions will need to involve partnerships that go far beyond health services.

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In December 2021, the [Child of The North report](#) provided compelling evidence of why a relentless focus on health inequalities is a moral, ethical, and economic imperative. The report provided a harrowing account of the appalling situation facing huge swathes of children growing up in poverty within the North of England. The resulting cost to families is enormous, but so is the financial public burden that arises from our collective failure to support children within disadvantaged areas.

In Bradford, the lives of over 13,500 children and their families have been followed via the 'Born-in-Bradford' longitudinal birth cohort study. The Born-in-Bradford project monitors change over time and showed that the UK's lockdown exacerbated the problems already present before the devastating impact of the covid-19 pandemic was felt. Born-in-Bradford showed that the lockdown amplified the inequalities already plaguing the district. An increase in markers of poverty was found, with a substantial number of families experiencing multiple vulnerabilities. Food security decreased and physical health behaviours worsened. Mental ill health became rife, and the risk of poor mental wellbeing was higher with an increased number of families struggling financially. Digital inequalities limited access to remote education: South Asian heritage children had less access to computer equipment and the Internet compared to White British heritage children. Classroom inequalities increased with teachers expressing concern over the disproportionate effect on vulnerable children and children with special educational needs and disability (SEND).

In terms of health and risk factors among children and young people in HNY, the data are showing year on year increases in childhood obesity. A continuation of current trends would see an estimate of over 40% children aged 11 years being overweight or obese by 2040. This of course has a deprivation gradient - with estimates of up to nearly half of children aged 11 years by 2040 for the most deprived populations.

Another area showing alarming trends in HNY is in children's mental health. For example, around 1 in 6 children aged 6-19 years were recorded as having a probable mental disorder. There were also marked increases between 2017 and 2021 in a wide range of conditions including eating disorders and sleep problems, combined with sharp increases in levels of school absence.

7. INFORMATION MATTERS

The Renaissance, the Industrial Revolution, and the Digital Age show that information ‘tipping points’ transform civilisation. The invention of writing, the creation of the Gutenberg press, and the third industrial revolution have all driven economic prosperity and enhanced human health and education through improved information sharing.

In August 16, 1858, President James Buchanan applauded:

‘...an enterprise accomplished by science, skill and indomitable energy... more useful to mankind, than was ever won by conqueror on the field of battle.’

Buchanan was responding to Queen Victoria’s telegraphic message, celebrating the rapid sharing of information made possible by the new transatlantic cable. The cable made possible the exchange of messages in hours rather than days. It immediately revolutionised the UK’s economy, with traders able to forecast, buy and sell more efficiently. From where we now stand, we can see how the transatlantic flow of information drove the exchange of **ideas** that built our modern global society.

The ability to gather, interpret, and transfer information is now more important than ever. Humans have survived and thrived because of their ability to store, process, and transmit information; finding food and shelter whilst avoiding danger, and passing this information on to others. **Civilisations** grew because they created educational systems able to transmit information across space and time. **Science** provided formal structures for separating signal from noise allowing, for example, medicine to advance on the basis of reliable information and demonstrate cause and effect. **Information** theory allowed data to be stored in incredible quantities and processed at phenomenal speeds through the creation of computer systems.

We are living in an ‘**age of data**’. It has already transformed our business and our media. It has the potential to transform, and level up, the health, education, and life chances of citizens throughout the UK. But, it has not yet done so, and the cost is more than we can bear as individuals and as a country.

The same geographical inequalities identified by the ‘Child of The North’ report can be seen through the prism of *information inequality*. Our affluent areas are adept at harnessing information to build business opportunities and drive local economies. Their schools – usually supported ably by families - equip young people with the skills that employers and the country require and transmit the information that children need to make healthy life choices. Communities are more likely to engage with crime prevention strategies and to report antisocial behaviours to the police. Parents take responsibility for sharing information across education and health systems. This means that schools, for example, are better able to identify and meet the education needs of a child with SEND before problems become entrenched. There is a clear correlation – and, we would argue, causal link – between the information advantage of areas such as the South East of England in access to computers and broadband, and the proportion of children who benefit because their families possess the skills to take advantage of that digital infrastructure.

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In contrast, a disadvantaged community can be described entirely in terms of informational failures. Communities find it difficult to collate information and share their needs with public services. Families struggle to know how to access support and make the changes they need. Statutory organisations lack the contextual information needed to design efficient services, capable of adapting and working for the people they serve. Information sharing across public services is limited or non-existent. Whether this is due to shortcomings in technology, resources, or leadership, it inevitably leads to safeguarding failures and predictable tragedy (most recently, Star Hobson and Arthur Labinjo-Hughes). In disadvantaged communities, children do not acquire the information they need to live healthy lives, aspire or compete in the employment market. In turn, the skills pipeline is damaged and the potential for local business to drive transformation is limited.

Information inefficiencies lie at the heart of the inequalities blighting our nation. But there is hope, because information science offers solutions as well as a framework for understanding problems. We now have the foundational knowledge and capability to apply information theory to these deep, societal challenges. Achieving this goal would not only transform millions of individual lives; the required revolution in our information systems would place HNY at the vanguard of international data science - with all the commensurate economic benefits.

In the US, Silicon Valley stands as testament to the financial benefits of connecting Universities to business and applying information theory to the marketplace. HNY has the potential to be a world leader in the application of data science to *wellbeing* (including health, education, care, and entertainment), with an inevitable and significant boost to our GDP through the development of the underpinning AI, analytics, and visualisation methodologies (such as immersive technologies). We have the potential to make Humber and North Yorkshire both the best place to grow up, and the best place to start and grow digital businesses.

The recent Levelling Up agenda of the government calls for coordination of six 'capitals' - physical, human, intangible, financial, social, and institutional – straddling the responsibilities and tiers of government across the UK. To realise our vision for applying data science, we need *analytical engines* that can connect, and interpret information drawn from the six capital components. These engines would provide insights to decision makers on how services need to align and respond most effectively and efficiently to the needs of different people, in different places.

Bradford have built and tested the first **'Integrated Data Engine for Analytics' (IDEA) centre**. The West Yorkshire IDEA centre is a new, independent unit for the region – a virtual team, housed in the Wolfson Foundation Centre for Applied Health Research, bringing together the Connected Bradford team, N8 scientists and researchers with our communities and those designing, commissioning, and delivering front line services, to:

- Connect and draw insights from routine data held by education, health, care and policing services, to better understand risks and vulnerability, as they vary from place to place, community to community;

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- Build tools that can deliver data insights to front line professionals, help them share information, coordinate support, and guide their interactions with families;
- Use visualisation methodologies to help families, communities, professionals and policymakers understand and interact with data – enhancing the accuracy of data insights, improving transparency and trust, and allowing the redesign of systems;
- Link schools with health systems through its Department for Education funded *Born in Bradford Centre for Applied Education Research (CAER)*. CAER provides an operational arm for the West Yorkshire IDEA centre, allowing the application of data insights at pace in educational settings, and enabling place-based community engagement using schools as anchor institutions within localities.

WY IDEA science projects are already making a difference to the lives of the most disadvantaged communities, by allowing the WY IDEA centre to direct and improve design, delivery, and evaluation of services, with a current focus on autism and ‘early help’. The projects are only progressing because the WY IDEA centre fought for and secured the necessary combination of **permissions, mandate and resources**, from national and local government, families and communities, and our anchor institutions. These include:

- the support of senior leaders from Multiple Academy Trusts, NHS Hospital Trusts, NHS Care Trusts and Local Authorities across West Yorkshire;
- the Department of Levelling Up, Housing and Communities’ ‘Data Accelerator’;
- the NIHR Applied Research Collaboration, MRC PRP, and NHSA networks;
- the Department for Education funded programme of work on the use of routine education data to identify and support children with undiagnosed autism;
- the input and support of the Data Improvement Across Government group.

Our proposal outlines the operating model, resource requirements, and the impact that would be generated through the creation of a new – Humber and North Yorkshire - IDEA centre.

National Government would be an essential partner – and supporter – in this endeavour, helping to unblock, encourage, and incentivise the required bold leadership. In return, the HNY IDEA network would transform policymakers’ understanding of demand ‘on the ground’, facilitate its ability to predict need, and provide data tools for designing and evaluating the impact of policies (and public spending). Thus, the HNY IDEA centre would position HNY in a favourable position for inward investment.

Meeting community need in a sustainable fashion in Bradford

In Bradford, fundamental concerns around access to services and premature mortality - especially in some of our most deprived neighbourhoods – were identified through conversations with citizens via the ICB's Listening in programme and Bradford's research networks.

Connected Bradford was used to calibrate these concerns and elicit the detail. The scrutiny of geospatial data revealed a clear overlay of high deprivation with the highest prevalence of premature strokes and heart attacks.

This information was made available to community representatives and VCS colleagues with an offer of support. This resulted in a truly co-produced, regularly deployed, community-based clinic involving anchor institutions such as mosques and community centres as well as other key stakeholders - Primary Care Networks (PCN), Community Partnerships, Bradford Institute for Health Research, community wardens and local councillors.

Citizens learn about the community-based clinic through word of mouth, posters and digital media.

Citizens receive core elements of the NHS Health check such as blood pressure measurement and, if deemed appropriate by the PCN attendees, blood tests for cardiovascular disease, type 2 diabetes and kidney disorders (full blood count, urea and electrolytes, HbA1c, Lipid profile). Crucially, this data is immediately uploaded to the individual's own GP record, thus allowing appropriate follow-up with their own general practitioners should this be required.

The sharing of local data was key in winning support for this work, and data analytics remains an essential tenet of service delivery and sustainability.

This method of service delivery is allowing local citizens to access important prevention and early intervention activity without having to engage in a parallel care system.

Feedback from attendees has verified that primary care services are much easier to access with regards to a known condition or where tasks have been already performed.

All who attend a CHC have a code attached to their SystmOne record that allows us to view their subsequent health outcomes but in a pseudonymised form. We can verify new diagnoses and treatments and, with time, evaluate the impact of this work as well as how it might be improved.

The programme has been built on data analysis, community engagement and trusted relationships which have allowed us to broaden the offer to preventative health, social prescribing and further offers of support from allied organisations.

Our ongoing mixed-methods evaluation of the work is also inclusive and draws from the world of quality improvement. All individuals who participate in each CHC provide the information for tests of change, rapid feedback and evolving iterations of the community clinic.

8. THE PROPOSAL

1. Obtain investment from the ICB to start the process of 'Levelling Up Information' across Humber and North Yorkshire, through place based, data-led projects, supporting the most disadvantaged wards (as per the Core20PLUS5 framework). Every project will use data science techniques to capture and link routinely held information and lived experiences, ensuring projects address issues creating the greatest problems for communities living in these areas.
2. Projects will be led and driven by a new 'Integrated Data Engine for Analytics' (IDEA) centre. The IDEA centre will draw on the capacity and skills of the N8 Universities. The HNY IDEA centre will deliver data insights, create data tools to link professionals and empower citizens, and develop methodologies to help coordinate local services. The HNY IDEA centre will report to the ICB, with the ICB determining the priorities, allocating resources and ensuring coordination with existing systems.
3. The IDEA centre's leadership structure will bring in and empower leaders from a broad range of partners including but not limited to the health system, multi-academy trusts, local authorities, voluntary sector, businesses, and the police. An IDEA member will be expected to bring, and combine their individual authority and mandate, to give the IDEA an independent, objective voice and the authority to drive change across systems, led by the science.
4. The funding will support a programme of:
 - Establishment of the IDEA centre, securing research analytics and staff time. The creation of the centre will include funding to secure population health and sector specific analytical expertise together with project management resource to administer and manage the programme.
 - Data driven projects across defined localities (e.g., LSOAs, wards etc), each aligned to local priorities, including work with communities, to co-design better, more effective and efficient local systems;
 - Integration of academic partners with the ICB through joint funded positions (including internships, MSc and PhD degree projects) and the launch of an annual 'Applied Data Science prize' and scholarships to attract the brightest minds to act on the hardest societal challenges.
 - A data pipeline to national government with the HNY IDEA able to provide a more accurate, composite picture of need, and enhanced capacity to evaluate impact, informing policy making.

The IDEA will be expected to attract inward investment (e.g., from HMG and UKRI) based on its demonstrable impact and value – including its value as an academic centre, as well as in improving the efficiency and effectiveness of public services. IDEA will attract UKRI and central government funds and ensure that the funds are applied to the most pressing societal problems.

The challenge and the vision:

5. The West Yorkshire Integrated Data Engine for Analytics is built on the **Born in Bradford** longitudinal birth cohort study¹. Evidence from the study shows, clearly, that in places where inequality is greatest:

- Families are significantly more likely to face multiple challenges (multiple vulnerabilities)
- Early and coordinated intervention is more effective, and cheaper
- Every failure to act early has a cost, to the individual and to the public purse, in lost opportunities and earning potential, and by creating demand for more expensive remedial interventions, later in life.

6. These issues are currently assigned separately to 'care', 'education', 'health', 'policing' etc. But they are experienced together within an individual's life; intersecting and multiplying to present ever more complex challenges for families, professionals, and those designing and overseeing delivery.

7. To respond effectively to these complex challenges, HNY will need its:

- People and communities; empowered to:
 - Understand healthy behaviours
 - Contribute to policy decisions that affect them
- Front-line professionals; connected, able, and empowered to:
 - Share information and identify risks earlier
 - Work as a team to deliver a coordinated, effective, and efficient package of support
 - Simplify and reduce the burden on families [single point of contact].
- The HNY ICS and Partners; connected, able, and willing to:
 - Understand patterns of [multiple] vulnerability as experienced by families;
 - Assign support more accurately and efficiently to the right localities and households;
 - Evaluate the true impact and value for money of 'whole system' interventions.
- Government and national bodies:
 - Connected to, and able to read, and respond more accurately to patterns of vulnerability and predictive factors, shaping demand for services, and varying approaches by place and population
 - Confidently able to define effective practice, in design, delivery and governance of local data-led systems
 - Leading local systems through the transformation required to achieve these goals: providing permissions and the mandate to act boldly, and together, at local level; releasing resources and deploying inspection and

¹ Insights drawn from the ongoing 'Born in Bradford' longitudinal birth cohort study, tracking the education, health and care experiences, and outcomes, of >13,500 children and their families, in Bradford.

other levers of accountability to ensure the highest standards of delivery for the most vulnerable citizens.

An Integrated Data Engine for Analytics: what is it and what will it deliver?

8. An Integrated Data Engine for Analytics (IDEA) centre is, in essence, a virtual team, operating at sub-regional level aligned to the ICB geography, creating a shared space for:
- Data scientists and researchers (spanning education, care, health etc) from our world leading research-intensive Universities within the North of England (N8)
 - Analysts and data scientists from across local health, care, education services, police, fire and rescue institutions (including schools and research schools, where available)
 - Social scientists who can provide ethical and legal guidance (including Information Governance Experts)
 - Data engineers who will develop and support the technical infrastructure and align efforts with NHSE Secure Data Environment initiatives
 - Local service Front line professionals and commissioners
 - The public and community organisations

...with a mandate and resources to build and deliver

- Connected local data sets – currently held separately by each service, to reveal risks as they play out and interact across a child’s education, health and care...and to support research into fundamental and treatable problems (generating new and more effective practice)
- Data tools, drawing on connected data sets, to help:
 - Commissioners and senior leaders build a more accurate picture of local risk and demand, assign resources, and evaluate impact
 - Frontline professionals, identify risk and intervene together, supported by secure, effective information sharing. This will and must include the urgent and practical requirement to alert the system where children risk falling through the net.
- Visualisation tools: allowing front line professionals, families, and communities to model and design more effective future systems, enabling genuine co-production and evaluation of impact.

...allowing

- Local services to reshape and respond more effectively – together – to the challenges faced by families and communities in the most disadvantaged localities. The IDEA centre will allow local services to evaluate the impact of their interventions, enabling evidence-based policy making to become the norm.

9. **Reach:** in the first phase, we propose the HNY IDEA works with three localities (identified by Directors of Place). The local areas will be selected according to IMD data in line with Core20PLUS5 but informed by local knowledge on the quality of the data assets, the

community readiness level, and community priorities etc. The plan will be to scale via a 'test and learn' approach ensuring that the shift towards preventative work does not create a burden on current service delivery.

Working examples: the West Yorkshire IDEA in action

10. Evidence already exists that an IDEA can improve outcomes for children and young people. The West Yorkshire IDEA has identified 'red flags' in routine data capable of identifying children at risk of autism. With the mandate secured from local health, local authority, and school leaders, the WY IDEA have designed and tested novel approaches to screening and meeting the needs of children with autism faster, and more efficiently. This is the SUCCESS² programme, which is now being rolled out across the UK. The Glasses in Classes work related uncorrected vision to reading outcomes and created new approaches to removing health barriers to education. These projects empowered schools to provide support as soon as a child's needs were identified, and subsequently integrate effectively with specialist health teams who could conduct their work within school settings in partnership with the school and family. The datasets within Connected Bradford allowed a scientific investigation into the impact of classroom-based Air Cleaning Technologies on health and education during the pandemic.

Building the IDEA network

11. Engaging local health, care, education services, and schools: This is the biggest challenge. While ICB arrangements draw leaders of systems together, and set a helpful direction on integration, the ICB remit per se is too limited to achieve the IDEA vision at pace. Our experience is that while local services are quick to commit to the principles of 'joining up', there will be three practical challenges to overcome:

- Resources are scarce and particularly stretched in the areas we need to target
- Accountability arrangements, including guidance and inspection, do not provide sufficient encouragement or leverage to senior leaders, to put in place effective, whole-system responses. This includes information sharing as well as freeing up professionals to work together
- Our experience is that senior leaders are more reluctant to commit permissions, resources or people to collaborative projects when services are under pressure, because doing so requires them to accept greater accountability for services they do not control
- Schools do not always find it easy to contribute to strategic discussions, raise concerns to or speak with authority, on health, care and other issues affecting their pupils despite evidence clearly showing the contribution that schools – particularly our strongest MATs – can make and the benefits they can draw from being involved in whole system programmes.

² Supporting Understanding of Children's Communication, Emotional and Social Skills

How will the N8 and ATI support this programme?

12. A single point of oversight and challenge: Vulnerabilities multiply, affecting multiple services, requiring the HNY IDEA to act as one in overseeing, challenging, and supporting this work. Senior stakeholders need to provide oversight, and this can be provided through an Oversight Group that draws on expertise from the N8 and the ATI. Ideally, the Oversight Group would include representatives from our universities, HMG departments and professional bodies (e.g., RCPCH).

13. School leadership: The IDEA structure creates a role and a mandate for school leaders – we would encourage representation from the leading MATs on the leadership group of the IDEA centre. DfE support in recognising [not mandating] the value of that contribution would be helpful, and we propose working with the DfE to create this environment.

14. Explore options to test/adapt inspection frameworks and align guidance, making explicit expectations that ‘good or outstanding’ services will be proactive in:

- Linking information, to more accurately assess the challenges faced by local people, as they vary by place, community, geography etc
- Engaging the research community, to learn from and, in turn, inform understanding of what effective and efficient delivery looks like
- Identifying barriers that prevent or dissuade front line professionals from working together, where doing so would reduce burdens on families, costs, and speed up intervention
- Developing effective practical and oversight processes to ensure the ethical and transparent use of information, to build and retain public trust and engagement.

15. Create a community of practice. There is an urgent need to create a new community of practice in Applied Data Science with a leadership role for the HNY IDEA. The community of practice would create common ground and, importantly, a common language, through which researchers, data scientists, national and local policymakers, professionals (and those who train them), could see, challenge, support, and learn from creative approaches. The HNY IDEA centre would support the wider analytical workforce and other regional and national CoPs (e.g., the Alan Turing Institute).

16. A specific strand of activity delivered through the community of practice would be a ‘critical friends’ programme – allowing local systems developing new data-led approaches to match with other systems, keen to explore similar ideas. There is no such community at present. Creating one would, for relatively little expense of time or money, accelerate the development and spread of effective practice. For the HNY IDEA, the community would offer unparalleled, focused access to groups of researchers and professionals, working together, to understand and respond to the challenges faced by our most disadvantaged communities.

17. Leadership of the community would allow the HNY IDEA to focus discussion and activity on policy priorities, concerns, and ideas. This would make it much easier to access the resources and expertise available to support development, test, and evaluate new data initiatives. These resources and expertise are mostly publicly funded. This relationship would increase the return on that investment.

The HNY IDEA structure

18. The HNY IDEA centre will take responsibility for:

- Coordinating activity, linking projects and sharing learning
- Monitoring progress and spending
- Organising the national oversight group

9. LEARNING FROM CONNECTED BRADFORD

Bradford has adopted two approaches that could allow delivery of the HNY IDEA vision:

1. Created a connected database that contains the health records of citizens across the Bradford District linked with education records, social care, policing data etc.
2. Identified legal pathways to allow organisations to 'reidentify' an individual in their care so they can efficiently and effectively connect with our public services to coordinate a 'whole system' response to an individual or family's care needs.

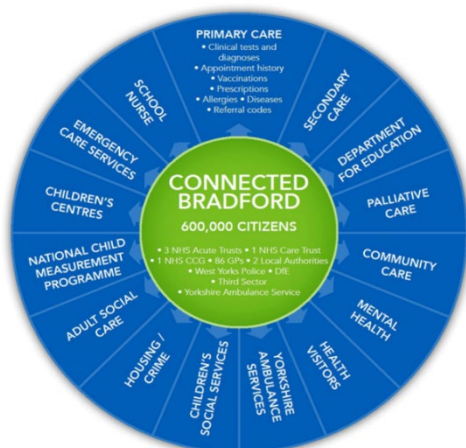
Challenge 1: Creating a connected database that can allow integrated decision making

Bradford has shown the power of connecting routine administrative records through the Born in Bradford (BiB) project. BiB is one of the world's largest longitudinal birth cohort studies and has linked routine data for over 30,000 Bradfordians. Frequent engagement with the families and children has ensured the Bradford community are at the heart of these efforts and allowed continued routine data linkage (e.g., health, social care, and education records) in a transparent, co-produced, and ethical manner.

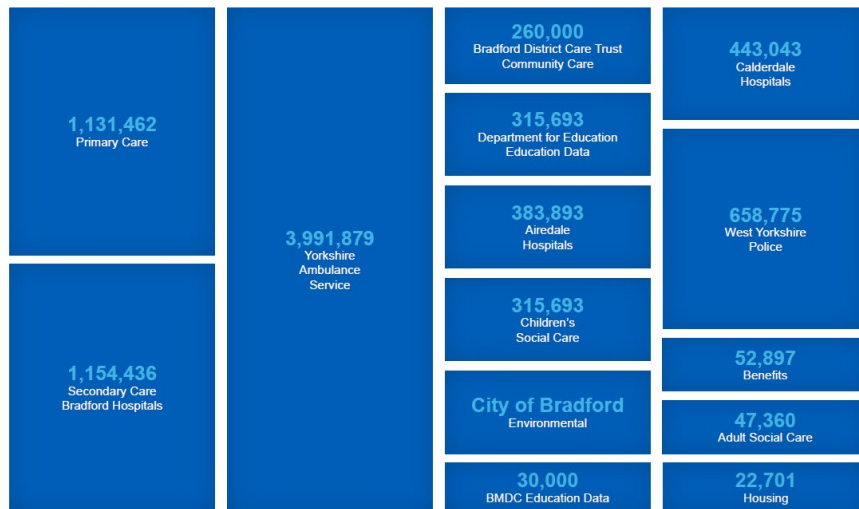
The success of BiB in using connected data led to the creation of the '**Connected Bradford**' database containing the records of citizens across the Bradford District. Connected Bradford combines administrative records, including primary care (e.g., appointment history, prescribing and clinical data), community care (e.g., mental health, school nurse, health visitor interactions), secondary care (e.g., maternity, outpatient), social care, children's centres data, education, housing and benefits, crime, housing data and data from the National Child Measurement Programme.

Connected Bradford sits within the NHS (the Bradford Teaching Hospital Foundation Trust) and provides a secure environment containing linked administrative datasets. The plan is to now migrate the database to the Yorkshire NHSE Secure Data Environment.

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Connected Bradford fact file



Connected Bradford is an incredibly powerful tool that allows extracts of data that can never be linked back to individuals. This allows decision makers to understand how different public services interact and enables a genuinely integrated approach to care.

Connected Bradford wish to work with HNY ICB to share learning and establish Yorkshire as the trailblazing site for innovative applied data science.

Challenge 2: Creating a digital tool to connect practitioners

The consequences of failing to use information effectively in public service delivery are catastrophic. It is rare to read a serious case review (Children's Act 2004) that does not highlight failures in information sharing across professionals and organisations. In December 2021, the tragic case of Star Hobson (Child Safeguarding Practice Review Panel, 2022) showed that our systems do not take advantage of scientific advances in data science.

Star is the personification of a wide malaise affecting families within the UK's most deprived areas. Connected HNY could help partners tackle these problems by connecting the routine datasets held by partners with a shared of responsibility for the wellbeing of families (e.g., health, education, social care, policing).

Bradford has already shown the power and feasibility of sharing information.

Connected Bradford wish to work with the HNY ICB to 'prove the principle' of data sharing 'Insights' platforms in a highly controlled manner as a first step towards wider deployment.

10. ASSETS AVAILABLE

The Connected Bradford team are leading a 'Secure Data Environment' (SDE) for Yorkshire (£8.3M investment) that could host Connected HNY. There are ongoing discussions involving HNY about the opportunities afforded by the Yorkshire SDE.

The SDE architecture will provide a technical solution for HNY Insights, but data sharing requires leading-edge data science, ethical deliberation, community engagement and co-production. This requires research partners.

The research-intensive universities across Yorkshire are able and willing to support HNY ICB.

The N8 (eight research intensive universities within the North of England) Child of the North initiative together with the N8 'Digital Health collaboration can provide academic firepower from a wide range of disciplines to help ensure the success of Connected HNY.

The Alan Turing Institute have offered support through their 'Digital Twins' programme.

Proactive Social Prescribing in York

York Centre for Voluntary Services, City of York Council Public Health and the York Health and Care Partnership have worked together to deliver a two-year proactive social prescribing project focussed on improving outcomes for individuals with respiratory conditions who are likely to be affected by the cost-of-living crisis.

Target population

People at very high risk of non-elective admission.
People with respiratory conditions (risk of harm from winter / cold homes).
People living in areas of deprivation.

Cohort

18+, IMD 1-5, COPD, very high risk of admission.
18+, IMD 1-5, Asthma, very high risk of admission.
18+, IMD 1-5, Bronchiectasis, very high risk of admission.

The Challenge - A requirement was identified in York Place within Humber and North Yorkshire Integrated Care Board (H&NY ICB) to create a proactive social prescribing model for targeting cohorts of patients who could benefit from targeted interventions. York Place received funding from the ICBs personalised care team to improve and deliver personalised care which was invested into the project.

With the current cost of living crisis and upcoming winter pressures, it was agreed that the social prescriber would deliver intensive interventions targeted at a specific, complex cohort of patients, particularly focusing on areas of deprivation across the city of York.

Our Response - The York Place team engaged with the local Commission Support Unit to develop a targeted algorithm that would run on our population health intelligence platform (RAIDR). A unique URL (SmartLink) would be created to identify patients living with respiratory conditions in Index of Multiple Deprivation (IMD) deciles 1-5 who were at high or very high risk of hospital admission in the next 12 months, as predicted by the combined predictive model (CPM) that is built in to RAIDR's Primary Care dashboard.

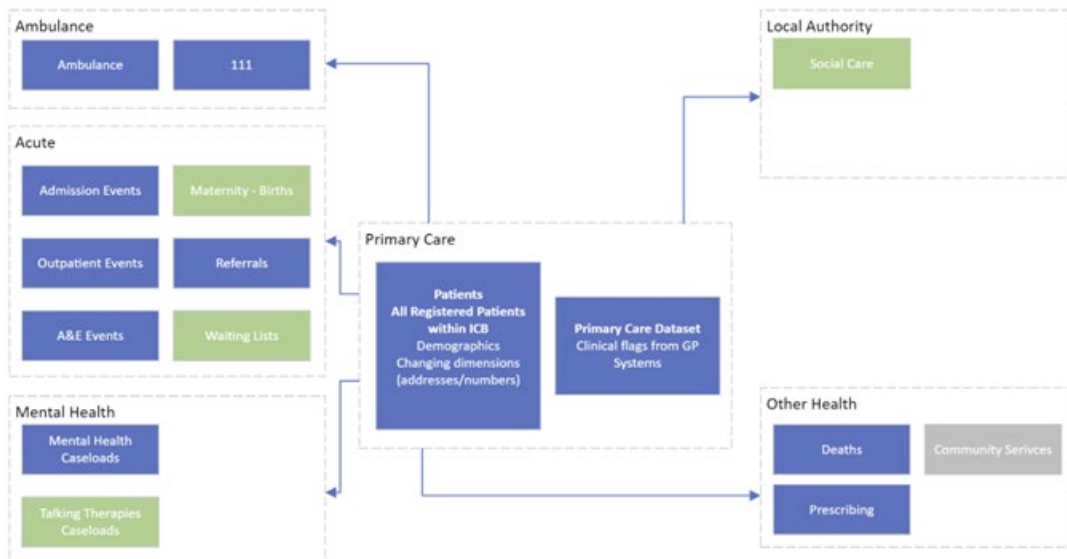
Defined patient lists are now available periodically for the social prescribing leader to easily access and assess.

The Outcome - The linked data presented via the population health intelligence platform has saved valuable resources within the ICB and has facilitated a multidisciplinary approach to the service, improving access and exploring more effective patient pathways. To date, the social prescriber has onboarded 51 patients, and this number is steadily increasing as the project gains momentum. The positive feedback received from patients has been truly uplifting, highlighting the impact of personalised social prescriptions on their overall well-being.

11. TECHNICAL APPROACHES AND SOLUTIONS

Humber and North Yorkshire ICB use NECS's AXYM product for its local data processing. The potential synergy with the SDE will allow for sharing of data assets and people to work on development.

A single linked dataset for patients across the HNY geography is in progress, for the purpose of population health intelligence, along with strategic analytics within the system. The linkage and storage of this data, primarily around health, with some social data to follow. This data, centred on primary care, is a potential large-scale asset for the programme.



AXYM Development within Health and Care Structures

This approach will mean data collation and sharing can happen once, with subject matter experts and local understanding of the data able shared. Governance processes will allow for the secondary use of data in an appropriate and ethical manner.

The availability of similar technology across local and regional SDEs will allow the technical development of two-way data flows.

Our ICB level linked data platform could also provide central hosting for additional connected data (beyond health and care) for our places, particularly where there is shared support and/or linked to local collaborative working.

12. PRINCIPLES FOR EFFECTIVE ACTION WITHIN THE HNY IDEA

- 1) Our data shows we must act *now*. It also tells us *where* to act. Our research can tell us *how* to take action. Partnership will be vital.
- 2) Effective partnerships are founded on strong, shared principles, which shape decisions and interactions through planning and delivery. This plan will require an unprecedented breadth of collaboration, commitment to community engagement, and an openness to change both culture and practice. Successful delivery will require a joint commitment to five key principles:

Principle 1: Clear accountability and authority

Principle 2: Recognising localities and empowering people

Principle 3: Making a reality of multi-agency working

Principle 4: Putting evidence at the heart of planning and delivery

Principle 5: Investment for growth

- 3) **Clear accountability and authority**, enabled by:

- a. A single point of leadership, with dedicated resources and a mandate to challenge and influence delivery across other services...to drive change and, where necessary, influence deployment of resources and people behind the plan
- b. A single, clear and short management chain, enabling clear sight of issues, accelerated decision making, and clarity of communication

- 4) **Recognising localities and empowering people**

- a. A prioritisation and focusing of resources to the localities, communities and individuals within the most disadvantaged wards
- b. Putting people and local professionals and organisations at the heart of design and delivery – improving our understanding of issues by testing evidence; ensuring interventions connect with people’s lives and the issues they face; generating a community mandate for change; and building a sustainable local leadership.

- 5) **Making a reality of multi-agency working**

- a. Giving professionals at the front line the freedom and support they need to connect, understand, and act together. This will include removing ‘artificial’ barriers (non-legal) on information sharing, pooling budgets, targeting criteria, and aligning operational processes.
- b. Activating and drawing on networks of practice – learning from areas (e.g., Bradford) and partner organisations that have a track record of creating change with an equal commitment to share and celebrate learning.

6) **Put 'R&D' at the heart of strategy and delivery**

The breadth of academic expertise available to drive action is matched only by the enthusiasm of researchers to engage with real challenges. We need to be prepared to learn together - not just on interventions but also to create a shared culture, enabling a virtuous cycle of learning through evidence and practice, research, and practitioners.

7) **Bring investment**

Our communities deserve opportunities for growth. Better jobs and opportunities for culture and leisure are shown to protect against vulnerabilities. By engaging and understanding places and their people, the plan will also help our businesses and enterprise initiatives to target investment more effectively and drive social mobility.

13. CHALLENGES AND OPPORTUNITIES

We recognise the challenges in creating this transformational change. In creating our guiding coalition of cross-sector leadership we have identified a number of areas where we are determined to remove barriers and create solutions. These would include;

1. Ensuring there is a legal basis for using the data, we are confident that this issue can be addressed. Additionally, we recognise that citizen consent is fundamental to the success of this venture. To that end we have started to empower local leaders in 'place' to use their existing collaborative networks to engage local parents, families, and professionals to build an environment of trust.
2. We will be required to have specific stated uses for the data from which we will not vary. We already have several case studies from across our health and care system that give us the confidence that we can achieve this.
3. We will need absolute transparency in terms of the planned and actual use of data. So, working at a local level with our communities will be imperative in creating a sustainable relationship between participating organisations, their professionals and across local communities.
4. We will require an oversight and governance model that gives confidence to everyone involved that we would do what we say we will. This model of governance will involve inviting representation from citizens and professionals to maintain trust and sustain the integrity of our venture.
5. Our delivery model will require the lowest unit of implementation. Therefore, we recognise the need and value of working in specific neighbourhoods and identified cohorts of families. This will require us to empower professionals at a local level to work with families and their data. These professionals could include teaching staff, social care workers, healthcare staff and police officers.
6. The workforce dimensions of implementation will require us to train and support across all our relevant professional groups. This will take time and expertise, so starting small, keeping it simple at first, and building from success will be our proposed approach.

Recognising these challenges and risks to our venture creates for us the opportunity to prepare for them in an inclusive and transparent way. The values of inclusivity and transparency will underpin our transformation.

14. PREPARING FOR DELIVERY

Connected HNY requires a system level solution to connecting complex datasets. This work could and should happen in parallel with smaller projects that can 'prove the principle' of connecting datasets. The application of Connected HNY projects should be delivered in a highly controlled manner, targeting specific localities, and focussing on a small number of priority areas. This approach will ensure community engagement providing support for the creation of the supporting datasets – but allowing the system to grow in a manageable fashion.

This plan assumes that localities will vary in the issues they prioritise, as well as in how best to engage people and services in planning and delivery. Each locality will develop and own its own delivery plan, bound together and driven by the clear leadership described above. A consistent sequence will be followed to define the locality plans:

Stage 1 – Identifying and defining areas

- Using individual service data and other information to define suggested localities, based on clustering of issues
- Auditing need (proportion of demand on different services against district totals) and cost of demand
- Identifying resources – services, projects, facilities, groups, businesses available to localities
- Identifying authority – decision makers and representatives able to influence the pattern of delivery of identified resources

Stage 2 – Describing areas – scoping and prioritising

Learning from Born in Bradford's Act Locally project funded by the Alan Turing Institute. The methodology allows clustering of people, practitioners, researchers, policy makers within a locality - identifying priorities, describing the impact of issues in data, and lived experience.

Stage 3 – Developing and refining models

Analysis and consultation to produce more accurate representations of issues playing out, and to identify points of leverage – where systems and processes could be changed to make interventions more effective and efficient. This stage must include assessing the potential for investment – in capital, infrastructure, organisations, and individuals.

Stage 4 – Proposals for change

- Delivery planning – describing how individuals, services etc will be realigned and resources and investments targeted
- Setting goals, evaluation criteria and methodologies

Stage 5 – Delivery

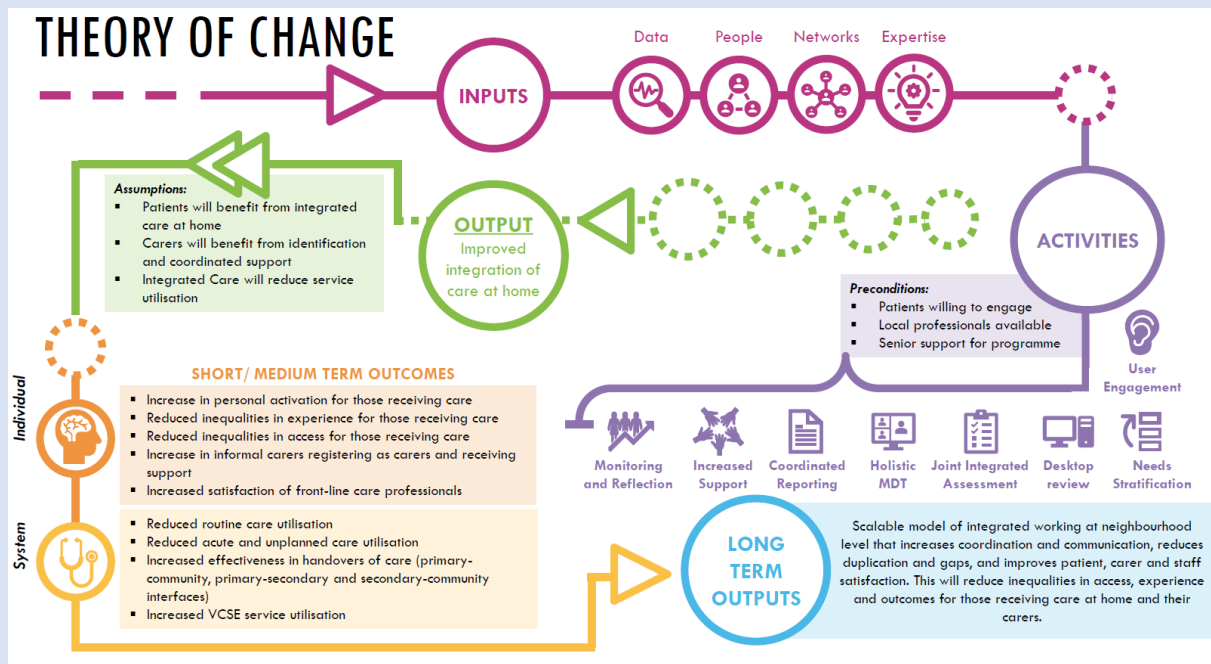
- Launch
- Oversight, monitoring, and challenge through new, clearer governance arrangements

Home Care

Home Care provision is a critical element of our community care provision. It enables people to remain independent at home for as long as possible and to return home from hospital more quickly with care and support. It can help prevent or delay escalation in need that results in hospital admissions or permanent admissions to residential care.

Hull Health and Care Partnership focused development of Integrated Neighbourhood Teams around home care services. An initial model of an Integrated Neighbourhood Team was developed using a “test and learn” approach in a small, highly deprived location of Hull. The Team involved a single PCN, Adult Social Care, the homecare provider, community services and VCSE organisations.

Data were shared by Adult Social Care on patients in receipt of home care services with the PCN. This enabled identification of patients within the PCN who might benefit from the integrated neighbourhood teams approach. Consent for data sharing was covered within the Yorkshire and Humber Shared Record Agreement as well as consents sought at the initiation of adult social care services, enabling rapid transfer of information.



The programme has developed improved relationships between individuals receiving care at home and their GP Practice, complementing the ongoing support available through the adult social care team. This is creating an avenue for continuity of care through the care coordinator which expedites access to appropriate care and support for patients. Patients are actively followed-up by the team where appropriate, often in a coordinated way so adult social care and primary care follow-up together. While individuals may be discharged from the MDT caseload, they continue to receive ongoing care from all agencies ensuring the impact of the intervention is sustained beyond the period of MDT working.

15. TEST CASE IMPLEMENTATION EXAMPLE

We propose that the HNY IDEA takes advantage of existing work in Bradford that will immediately allow data driven place-based approaches to be adopted within HNY. Bradford have developed an electronic tool (the Electronic Developmental Support Tool, EDST) that addresses the current autism assessment and support crisis. The EDST provides a vehicle through which information can be shared across health and education for a well-defined purpose. Most critically, it brings together health and education practitioners and drives discussions about the need for effective information sharing. This will help engage communities with the HNY IDEA from the outset but also lay the ground for the practical implementation of information sharing systems. It will also help address a major problem afflicting health and education with immediate effect.

The Electronic Developmental Support Tool (EDST): Supporting schools in the early identification of children's learning needs

The evidence is clear – some children experience delays in acquiring fundamental learning skills (FLS). A delay in the acquisition of FLS can hinder a child's progress in school. In the long term this can have profound negative consequences for a child's educational attainment, social mobility, and physical and mental health.

The evidence is equally clear – school staff are experts in identifying delays in the development of FLS. However, pinpointing these needs and knowing what accommodations and support needs to be put in place can be difficult.

The Electronic Developmental Support Tool (EDST) helps school staff record a child's FLS across a range of domains and then offers evidence-based suggestions that can help the school support a child's needs throughout primary school.

What is the EDST?

The EDST produces a simple report summarising each child's learning and support needs. The tool automatically suggests evidence-informed approaches and interventions that can be put in place immediately by school staff (sometimes avoiding the need for referral and a lengthy wait for specialist services).

In situations where specialist input is required, the rich information collected through the EDST can be shared with other professionals (e.g., educational psychologists and/or health services). The EDST is therefore an approach that can help create a more connected support system for children and their families.

All staff within EDST schools participate in a course on neurodiversity. The course discusses how schools can become 'neurodiverse friendly' environments and highlights potential strategies or practices that can be put in place for children who need additional support.

The course also provides training on how schools can work effectively with health services for those children who need specialist medical support for learning needs (e.g., autism and ADHD).

How the EDST works

The tool helps teaching staff identify children's learning and support needs by asking them to rate a child's acquisition of key developmental skills against expected levels for the child's age. These key developmental skills are based on four areas of need: "cognition and learning"; "communication and interaction"; "socioemotional and mental health"; and "sensory and physical" skills. This information is used to support a child with immediate effect but can be shared with health practitioners when a child is placed on an autism assessment waiting list – providing a useful test case of data sharing across health and education.

This new digital tool takes advantage of the unique ability of school staff to observe individual children over long periods of time, in comparison to their peers, and track a child's progress at multiple time points throughout a child's educational journey.

The process facilitates a discussion between school and parents by automatically generating letters to be sent home. If need is identified, parents are offered the opportunity to help complete the EDST to reduce the risk of needs being missed due to 'masking' (where children hide their difficulties – an issue particularly prominent in girls and ethnic minority groups). Thus, the EDST is designed to help schools build partnerships with parents.

Why the EDST is useful

The EDST increases the likelihood of a school gaining a more holistic picture of a child's strengths and difficulties throughout their primary school education and reduces the risk of children with unmet needs falling through the net.

The EDST will enable children's needs to be recognised and supported at the earliest opportunity and allow tailored adjustments/interventions to be implemented.

This approach will give children the best possible start in education and ensure they are sufficiently supported throughout their educational journey.

The background context

Research has demonstrated the ability of early statutory assessments conducted by schools - such as the Early Years Foundation Stage Profile (EYFSP) - to identify unmet need (e.g., a child later being identified as having Special Educational Needs or autism). However, the EYFSP was never intended for this purpose.

Research shows that children with additional needs can thrive in mainstream education if their needs are adequately supported in a timely manner.

Traditionally, schools received comprehensive support from educational psychologists in identifying additional learning needs. Unfortunately, educational psychology services have been cut to the bone and there is therefore a need to empower schools to pinpoint delays in a child's acquisition of fundamental learning skills.

The system level problems are compounded by the current 'autism crisis' where large numbers of children within school have conditions such as autism but are waiting many years before they receive a specialist evaluation within the health system. The EDST can help schools better understand the needs of such children and provide support during the lengthy waiting period.

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Moreover, the information gathered by the EDST can ultimately help speed the assessment process. In addition, schools will be better able to distinguish children needing health service support from those who are able to reach their learning potential with only light touch adjustments within the home and school.

The EDST is an important step towards creating a 'needs-led system' and helping us transition from the current 'diagnostic-led system'. The long-term vision is for the EDST to help create a system where all children receive the support they need to thrive.

What the EDST does

- Highlight children who may benefit from additional support within the classroom (whether that be light touch adjustments or interventions).
- Identify learning needs.
- Help the school consider the perspectives of parents/carers (helping teachers to more easily identify children who may be masking within the classroom).
- Help schools and families obtain information on what the evidence suggests is the best way to support a child's specific needs (i.e., by tailoring recommendations for support).
- Support teachers in making referrals and provide clinicians with additional information in making diagnoses (if this route is chosen)
- Track progress throughout a child's educational journey.
- Support teachers to deliver high-quality teaching (previously known as 'quality first teaching') by providing a framework to tailor teaching to children's additional needs.

What the EDST does NOT do

- The EDST DOES NOT classify a child as neurodiverse, neurodivergent, or having a neurodevelopmental disorder (including, but not limited to, autism or ADHD).
- The EDST DOES NOT identify which children should be added to the SEN register.
- The EDST DOES NOT recommend that a child should be referred for diagnosis – this decision lies in the hands of teachers and parents/carers.
- The EDST DOES NOT replace diagnosis – parents/careers and teachers will still seek a referral/diagnosis if they believe this is best for the child (and their family).

The scientific framework underpinning the EDST

The following framework is made explicit in the whole school EDST training, and in general communications, when explaining the purpose of the EDST within the context of UK systems.

1. Neurodiversity

The EDST celebrates neurodiversity and provides training on the differences (both strengths and difficulties) that school staff may see in their students due to the natural variation in human cognition. However, while this project highlights the beauty of our differences, it recognises that sometimes differences can cause barriers, particularly barriers to education, if society does not make reasonable adjustments for difference. Not addressing these barriers can prevent children from achieving their full potential (see the 'models of disability' point 3).

2. Language

Unfortunately, some of the language adopted in international and national legislation is unhelpful and does not reflect the language preferred by those with lived experience. Nevertheless, it is necessary to recognise the existing legislative terminology when discussing system reform to avoid confusion (noting that this does not preclude a change in terminology in the longer term).

3. Models of disability

The World Health Organization's (1980) International Classification of Functioning, Disability and Health ([ICF](#)) provides a useful framework for considering an individual's functional abilities within the context of their school environment.

The ICF defines disability as an inability to participate and engage in activities of daily living (which for children clearly includes educational activities).

The ICF emphasises that neurodevelopmental differences can cause disability if the environment (or activities) are not modified to accommodate these disparities. This serves as a useful reminder that a child's 'disability' can be removed or decreased by adjusting activities and the classroom (this does not preclude helping a child acquire a core learning skill).

4. Specialist health service support (via a diagnosis) is sometimes needed

Healthcare professionals diagnose 'neurodevelopmental disorders' (the term used within legislative frameworks – see point 5) using tools that standardise observations of how someone behaves in a particular situation (the EDST cannot replace these tools but may be able to provide more information to clinicians at the point of referral if a diagnostic pathway is taken).

It is important to emphasise that the observed behaviours lie on a continuum, with large proportions of the population exhibiting such characteristics. The diagnosis is therefore based on a clinical threshold where the behaviours are deemed to be occurring to an extent that warrants specialist healthcare support.

NHS England outlines four major advantages to this approach:

- (i) It enables clinicians to recommend interventions that have been tested for safety, acceptability, efficacy, and effectiveness with people who face similar challenges within society.
- (ii) It ensures reasonable adjustments are made in general physical health or mental health services (given the association between neurodevelopmental disorders and the increased risk of poor general health).
- (iii) It helps develop a positive self-identity and foster connections with the neurodivergent community.

- (iv) It facilitates access to some forms of statutory protection beyond the healthcare context.

There are three critical points to make in the context of the above:

- Children are constantly developing, and upstream experiences will shape their behaviours at an older age. This means that a child provided with adequate support at an early age may fall below the clinical threshold and subsequently not need specialist healthcare support.
- Many children will not reach a clinical threshold but still need learning support. There is, therefore, a danger that children who have traits associated with neurodevelopmental disorders but do not reach clinical diagnostic thresholds may fall into the gaps between health and education.
- The need for specialist healthcare does not imply that the responsibility for support falls on healthcare services. Appropriate support should be also provided within homes and education settings.

This consideration exemplifies the requirement for a needs-led system but also highlights that some children will need medical support (accessed via a diagnosis) that cannot be provided by schools. There is great potential for a needs-led system to work in harmony with diagnostic health pathways (dependent on the wants of the child and their family).

5. Neurodevelopmental disorders

Neurodevelopmental disorders are not illnesses or diseases but encompass terms that can describe people with a specified collection of behavioural characteristics. For example, the World Health Organization (2022) categorises autism as a neurodevelopmental disorder within its International Classification of Diseases (ICD-11).

ICD-11 is the framework used within UK healthcare to diagnose neurodevelopmental disorders (where other examples include Attention Deficit Hyperactivity Disorder, Developmental Motor Coordination Disorder, and Dyslexia). *[Note that, in the US, the American Psychological Association's (2013) Diagnostic and Statistical Manual of Mental Disorders (DSM-5) is used instead, but there are only minor differences between ICD-11 and DSM-5.]*

6. High quality teaching

The EDST aligns to recommendations made as part of 'high-quality teaching' (previously referred to as 'quality first teaching'). The EDST simply provides teachers with tools to support this approach.

First, the electronic tool helps teachers to recognise, document and monitor a child's needs more easily. Second, the suggested recommendations are either adjustments that are endorsed by educational psychologists, or evidence-based interventions. Importantly, all advice is specific to the needs identified by the EDST. Finally, the ESDT

instantaneously provides teachers with several suggested courses of action, allowing them to select the most appropriate approach for each child. This reduces the additional burden placed upon teachers in terms of having to source and evaluate this information themselves.

Beverley Road Corridor Project - Our People Our Place

The Hull Place partnership introduced the 'Our People, Our Place' initiative to identifying priorities beyond traditional health and care issues by focusing on the wider determinants of health. The initiative was a collaboration where a range of agencies shared data and coordinated comprehensive, cross-disciplinary services for individuals and families within the Beverley Road Corridor area of Hull.

The partnership created a Business Intelligence mapping dashboard that consolidated 51 indicators across 8 partners by area postcodes. The dashboard enabled an efficient review of needs and activities and identified patterns of demand across agencies.

The Partnership identified 10 postcodes with high needs and frequent service use. One postcode stood out, with 1,127 instances of service use costing an estimated £543,000*. This included 100 calls to 111, 34 ambulance calls to 999, 37 mental health contacts, 187 uses of urgent care, 107 hospital bed days, 43 social care contacts, 68 police calls for crime and anti-social behaviour, 11 fire service calls, 119 police calls for service, 76 housing benefit claims, and 2 troubled families. Across all 10 high-need postcodes, the estimated total service cost was £2.82 million.

Working with Hull University, the Partnership established methods to intervene and assist residents of this area, preventing negative outcomes. The methods included:

- Improving interaction with health and social services by making them more accessible.
- Using data-driven targeting of vulnerable areas to deliver preventative, multi-agency mobile services.

The project had a soft launch, with a new project team based in the heart of the Beverley Road community on the former Endeavour school site. Leveraging the MEAM (Making Every Adult Matter) and MAVA (Multi-Agency Vulnerable Adults) frameworks, the Partnership concentrated on homes with multiple occupants.

This approach facilitated a new partnership dialogue centred on cross-sector demand for preventative support and enabled community and voluntary sector participation. It is anticipated that 'Our People, Our Place' will provide a model for other areas of the city as it develops, with learning from the project used to create increasingly person-centred innovative practice – where connected data can enhance the approach.

* Looked at a very limited range of the measures included in the dashboard (12 of 53).

16. ADDRESSING THE KNOTTY QUESTIONS ON DATA LINKAGE

The Futures Group identified five 'knotty' questions that need to be considered in the context of the proposal outlined within this document. The answers to these questions are given below.

What is the legal and ethical basis for using the data?

The legal and ethical basis for using the data has been established by the Connected Bradford team who will support the HNY IDEA centre through the process when establishing Connected HNY.

The HNY IDEA centre will include academics from the N8 Universities who will advise and guide HNY through the multifaceted issues that need to be addressed when establishing a connected database.

The process will be scrutinised by the External Steering Group and the processes captured so that other ICBs can follow the trailblazing work within Humber and Yorkshire.

Ethical approval will be sought to provide reassurances to data providers around the creation of a research database. The approval will include: a) the ability to add additional datasets to the database; b) allowing GPs to opt out of the wider use of the data for all pathway projects identified by the programme; c) allowing GPs to opt out of the process for extracting the pseudo data from the GP practice and d) extend the availability of the database to external researchers.

Ethical approval will also be sought to use personal non-unique identifiers and the need to develop a new research database for these linked data. This process will include application to the Confidentiality Advisory Group (CAG) for s251 approval under Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002. These approvals will include submission to the respective committees to flow personal identifiers to the Department for Education (DfE) to enable healthcare data to be linked with the National Pupil Database (NPD), social care data, and Geospatial information.

What specifically are we going to use the data for?

The data will be used for two purposes.

First, connected datasets will be used to create a research database that provides rich insights into the interactions and intersections within and across service delivery. This will, in turn, allow the deployment of academic expertise and resource against our strategic population health priorities at place and system level. The database would also allow HNY to draw on academic expertise for embedding evaluation, helping the ICB to better measure the success of local initiatives including population health management projects across PCNs, Integrated Neighbourhood Teams, and GP practices.

Second, the database will be used to test the principle of information sharing across practitioners in different organisations. In the first instance, this will involve the controlled sharing of information on a child's neurodiverse behaviours to health practitioners

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conducting autism assessments and information on the diagnostic outcomes flowing back to the school. This case study will; be used to explore the potential for more effective data sharing across health education, policing etc.

How can citizens see how their data is used?

Community engagement lies at the heart of the HNY IDEA centre proposal. The existing BABI process shows how citizens can be actively engaged in discussions about the usefulness of linked routine administrative datasets for driving improvements in population health.

The HNY IDEA centre will oversee a programme of work that informs citizens across Humber and North Yorkshire about the plans to improve integrated care delivery through the ethical, legal and transparent use of data.

Importantly, the HNY IDEA centre will work in specific localities trialling projects that address community priorities. These priorities will be co-produced with citizens and utilise data visualisations (using the 'Connecting Lived Experiences with Electronic Records' methodology developed in Bradford). This will ensure that citizens are actively engaged with every part of the process and reflect the ethos of the HNY IDEA centre where the voice of citizens lies at the heart of decision making.

What is the governance / oversight model?

Information Governance (IG) is a key challenge in accessing data, sharing data, hosting data, using data, and developing a linked dataset. The HNY IDEA centre will repeat the process successfully followed in Bradford. An independent IG consultant supported Connected Bradford's commitment to ensure that data from healthcare, local government and other partners is always shared securely and lawfully. This resulted in the programme developing a Data Protection Impact Assessment and data sharing agreements that outline scope, the data linkage pseudonymisation process, mitigations to identified risks and concerns, engagement activities with data providers and the public, legal bases, and information security. Further advice was obtained from the Information Commissioner's Office, with subsequent buy-in from the Local Medical Committee and the NHS Clinical Commissioning Group, to secure further reassurances for the regional clinical workforce before agreements were issued and signed.

What is the lowest unit of implementation to make our project successful?

The creation of a connected database that supports the analysis of data across Humber and North Yorkshire represents the 'minimum viable product' for the HNY IDEA centre. Connected Bradford have demonstrated that it is possible to create such a database and the HNY IDEA centre will be judged successful if 'Connected HNY' can be likewise established.

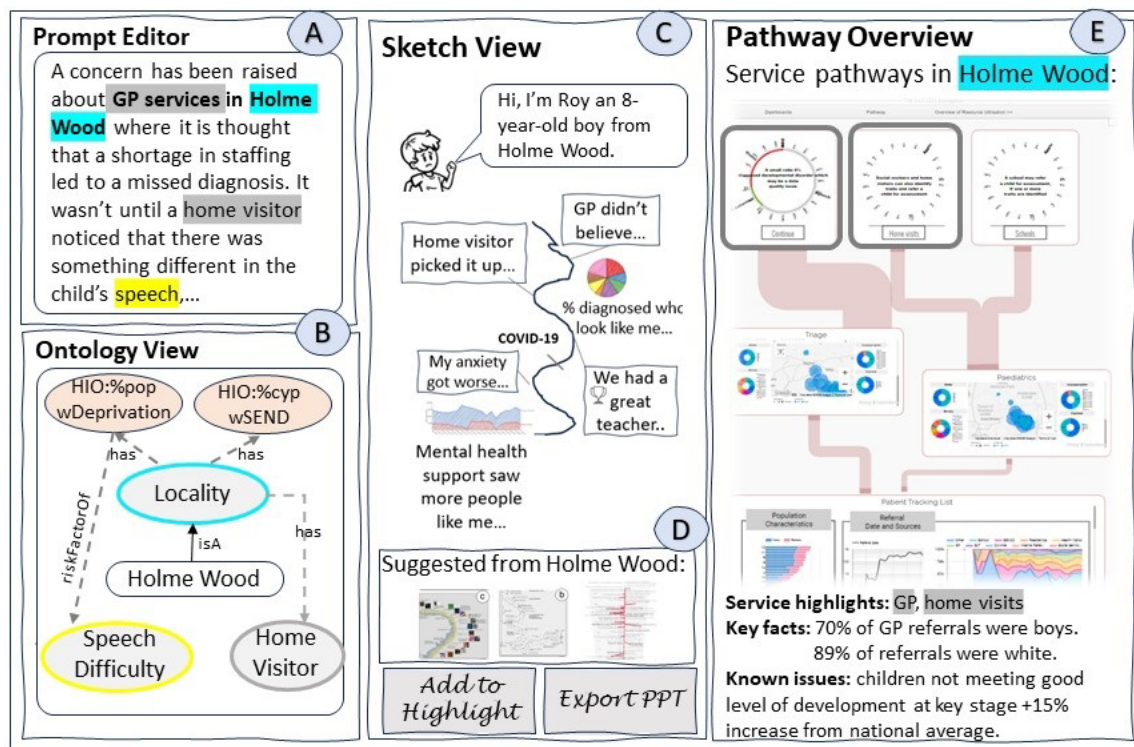
The vision for Connected HNY is the application of data science to directly improve the care provided to children, young people, and their families. Thus, the goal is to allow professionals at a local level to share information more effectively when working with families and their data. The implementation of such information sharing in three localities will indicate success and allow the HNY IDEA centre to scale this approach at pace.

17. CONNECTING LIVED EXPERIENCES WITH DATA

In public service planning and public health management, routine administrative data are often biased, incomplete, and inconsistent across services. These limitations mean that decision makers need to calibrate the insights obtained from datasets with qualitative data. These qualitative data are collected through co-production activities and help policymakers understand the lived experience of citizens and communities as they formulate a decision.

Data analytics and qualitative techniques provide useful insights, but the combination of these methodologies would transform the use of evidence in decision making. The ability to detect patterns across connected datasets and then work with communities to calibrate and understand the patterns would represent a step change in integrated care.

Bradford have created an approach for **Connecting Lived Experiences with Visualisation of Electronic Records (CLEVER)**. The approach uses visualisation as a central component in a complex adaptive decision-making ecosystem and structures domain knowledge across three decision contexts in Population Health Management (PHM): clinical, service and district. The CLEVER approach can transform the way data and soft intelligence are produced and presented to support decision-making.



Preliminary design for the CLEVER interface.

The HNY IDEA centre will allow Humber and North Yorkshire to benefit from the academic community developing visualisation tools such as CLEVER, and allow the ICB to combine insights from routine data and lived experiences in a way that could transform decision making.