Gofal Cymdeithasol **Cymru**
Social Care **Wales**

Strategic approach to social care data

Quick wins
Summary document

October 2021

Contents

Introduction

In phase two of the strategic approach to social care data, we worked with a small number of key stakeholders from government, local authorities, care providers and the voluntary and community sector, as well as citizens and practitioners, to formulate five ‘quick wins’:

The five ‘quick wins’

1. **Common standards for social care data**
2. **Develop roles and competencies for analytical roles**
3. **Design for citizen and practitioner engagement : look at how we engage with the community**
4. **Enable data sharing between local authorities, SAIL and other data sharing organisations**
5. **Put in place a new way to share data about the social care workforce**

This document summarises the approach, methods and findings from each of these quick wins, also highlighting the next steps where further work has been recommended.

The ‘quick win’ approach

As with any project of significant size there is a great deal to consider, many people to engage with and a lot of work to plan. Agile methods are different to traditional ways of project management as they allow different parts of the project to be carried out quickly from the start. Smaller pieces of work run alongside areas of work that need more time and space to develop and deliver, to maintain energy and interest in the project.

These smaller components are designed to be done quickly and take no more than several weeks, hence the term ‘quick win’. This type of rapid delivery occurs throughout the life of the project, which may run for several years. By maintaining this continual delivery, projects don’t become stagnant, development is always based on up-to-the-minute thinking and stakeholders aren’t waiting endlessly for products to be delivered.

‘Quick wins’ are by their nature limited in what they produce. Some are developed to kick off a conversation, some deliver prototypes or potential models of development, some will develop rapid solutions to problems, and some may deliver a physical product. They aren’t intended to replace more in-depth development, but to be part of a mixture of projects happening at any given time to create opportunities for continuous delivery and momentum.

We selected quick wins based on the priorities identified in our discovery report. Larger packages of work can be broken up into smaller quick wins that can be delivered one after the other. Other quick wins will crop up during the life of the project. The five quick wins described in this document were prioritised by stakeholders taking part in the project.

Elements of a ‘quick win’

Must be visible

Narrow in scope

Easy to implement

Inexpensive

Immediately beneficial

Can be completed in 90 days

01

Common standards for social care data

Background

During the discovery phase of the project, people agreed that consistently describing the data we collect is vital in developing a system-wide understanding of social care, which in turn would enable innovation and improvement to services.

However, we found challenges for data standardisation such as:

- **the scale of social care means defining standards that work for everyone is difficult**
- **agreement of definitions and unwillingness to adopt a standard**
- **differences in the way social care is provided**
- **a perception that data is only collected for 'performance measurement', reinforcing a suspicious attitude to the purpose of collection**
- **a lack of appreciation of data as an asset to improvement.**

This quick win brings together learning from three Welsh case studies, each of which needed to consider data and how data was described and standardised as part of their work. The product of this work has been the creation of a checklist that organisations should think about when carrying out similar work.

The checklist has been created to accelerate investment in data standards and quality and, in doing so, move forward the identification of shared data standards across Welsh social care. Data standardisation is challenging, but not impossible, with the right tools. Making a start needs a culture change, shifting towards a genuine interest in insight through data, supported by the right technology, skills and leadership.

The projects included in this quick win

Powys County Council

Powys County Council Social Services received a critical report from Care Inspectorate Wales (CIW) in 2017.

After enhancing their data capability and reporting, a later performance evaluation in October 2020 noted significant improvements, and that data had played a role in this.

WCCIS

The Welsh Community Care Information System (WCCIS), created to act as a shared electronic record for health and social care, developed by CareWorks.

Implemented so far in 15 local authorities, it's designed to give community nurses, mental health teams, social workers and therapists the digital tools they need to work better together.

Social Finance

Social Finance's work with local authority partners (Blaenau Gwent, Neath Port Talbot and Torfaen) to reduce pressure on the 'front door' and improve users' experiences of accessing adult social care, demonstrates how agile methods, user-centred design and digital transformation can improve services.

What we learned

A focus on standards for data sharing will be an important part of a social care data strategy for Wales. As a sector we will increasingly work together and align on the same standards to connect our systems (interoperability standards) and to understand our data in the same way when we exchange it (data standards).

Data standards and interoperability standards are strategic challenges and need discussion and co-design across sharing partners. Because of this, they aren't 'quick' by definition.

However, to help quickly share a set of standards and activities to inform more effective sharing of social care data, this quick win has gathered a set of best practice / standard activities and hygiene factors, informed by the three case studies outlined above. A checklist of those standard practices is on the next page.

Checklist for common data standards (1)

	Standard	Overview	What does this mean?
1	Standards for data help drive the quality and consistency of insight we all want.	Using data standards means data can be reused across systems. It's essential that there's a shared understanding and agreement on data standards for 'performance measurement' rather than a full technical description of the data.	It's possible to see how data can lead to better understanding of how it supports the system, and its potential to drive innovation.
2	Standards for interoperability help make sure we can share more quickly, safely, and consistently than we can today.	Interoperability is made possible by data standards that allow individual IT systems to share data, even when different vendors created the systems around different infrastructures. It automates information technology systems and software applications to communicate, exchanging data accurately, effectively and consistently, and to use the information that has been exchanged to generate insights that can only be obtained by combining the data.	The datasets held across health and social care in Wales can be combined to increase data accuracy, reduce the need for repeat data collection and drive better service outcomes and experiences for citizens and the workforce.
3	Recognise that enhancing use of data will take a great deal of behind-the-scenes work.	Behind a set of upgraded reporting is a lot of complexity which takes many years of work. But trying to adopt the surface level changes (for example, new reports) without the behind-the-scenes effort – the people, processes, technology, culture and development approach – is like having a car with no engine. Some things, such as building the environment, upskilling developers, change how the organisation views and consumes data, can take many years. Organisations should be prepared to embark on this long-term journey.	To use data more effectively, we need a programme of work and investment. Data must be treated as an asset, as important as other assets such as people or estates.
4	Create a positive culture around the use of data, starting at the top.	Begin by embedding data-driven insight in decision making by leadership and set the new expectation for the importance of data in the organisation. Continue by focusing on the tier of senior managers below leadership, then the rest of the organisation. Once people see what's possible, the 'data narrative' becomes self-sustaining and a data-oriented culture grows.	Creating a middle tier leadership group to sponsor data is one of the most effective ways to drive data change in a local authority. Empowering them to help set and deliver the agenda can make the difference.

Checklist for common data standards (2)

	Standard	Overview	What does this mean?
5	Upskill the workforce and encourage a self-service approach.	People should interact with data directly, to improve appreciation for its potential and remove steps from data management processes. At Powys, implementation of Power BI was critical to achieving this, by being dynamic, engaging and accessible for non-specialists.	User-friendly business intelligence (BI) tools and an investment in teaching workers data visualisation and basic BI skills. This is how to achieve impact and buy-in.
6	Be bold in promoting new technologies in support of the ambition for data.	For instance, at one organisation we saw that investment in the right BI tools meant data teams could share reports containing sensitive information to staff and other organisations while maintaining security. Leadership should visibly prioritise adoption of these new technologies and elevate them among their organisational priorities.	As well as BI tools, explore Cloud technologies, data storage and transformation solutions to give quicker, more democratic access to quality insight, and better outcomes.
7	Know which data really matters.	Not everything can be captured, investigated and analysed. It's imperative to consolidate datasets to a tailored set of 'highlight' indicators. Which data points really matter for understanding performance?	Some data sets are more valuable than others so knowing which ones provide greater opportunities or help reduce risk allows you to prioritise what to focus on first.
8	Combine data with other intelligence to get the most from it.	Experts in the service still have knowledge and understanding that informs the data. Organisations must ask *why* and dig into the root causes. Staff must be equipped to access and interpret data, and combine it with their experience and operational insights.	Heads of service and operational staff are at the core of defining and achieving outcomes. They provide the context for how data can help achieve those outcomes. They need to be involved alongside technologists.
9	Adopt agile transformation approach, for better use of resource and higher quality end products.	Features of agile include: a backlog; cycles of small sprints; daily touch points for teams; an emphasis on quick wins as incremental steps to bigger goals. Adopting agile also requires the right leadership approach and culture, such as stakeholders being willing to prioritise some new features over others in the near term.	An agile, more iterative approach to delivery allows you to test new approaches and see results more quickly. But agile is also a significant cultural change, not just a change in methodology. Training and coaching are critical.

Checklist for common data standards (3)

	Standard	Overview	What does this mean?
10	Make sure data teams have clear requirements from customers.	It's important that these requirements are signed off by customers before development starts.	Clear product owners are the ones who make sure what you need is delivered. To be effective, they need to be selected from among your most experienced staff and supported to make decisions about what's built. This isn't a part-time role.
11	Always refine and learn how to do things differently.	Never expect to reach an end state, for example, reports from previous years can be revisited as the organisation matures in its capabilities and needs. In this way, the user experience and product are constantly being refined.	Refining and learning is best done by building on success. There will be things that don't go well that will need correcting but, more importantly, things that succeed that can be made better; this can help drive momentum.
12	Where possible, look at what other councils and organisations have done and adopt best practice.	Get in touch and speak with them if need be. It's important to not just concentrate on Wales but to look further afield for pockets of good practice.	Making use of best practice from elsewhere can give the confidence to invest in new areas.
13	When designing or redesigning data, identify and understand the underlying business process.	Understand both the current process and the "to be". Achieve buy-in, particularly with operational leaders, about what these are. The approach to data should then be designed to fit what will be needed. Prioritise data efficiency and best practice in the final design. In particular, all data must have a purpose, rather than be collected for the sake of it. Data should be created once but used many times.	Your use of data enables your outcomes through a set of supporting processes. If you start with that in mind, you can focus on bringing the right types of data together to support those outcomes. As you make data available, think about making it usable for other initiatives, to avoid rework. It should be made available subject to appropriate information and programme governance approval.

Checklist for common data standards (4)

	Standard	Overview	What does this mean?
14	Establishing good, inclusive governance is difficult but worth it for data and technology programmes.	Questions around data can be highly technical and sometimes controversial. Where consensus can't be secured, there should be a clear escalation pathway to a forum that can resolve the issues. Motivated leaders who understand the vision should take and drive forward a final decision.	It's important to have the right governance body to make decisions about social care data and its use. The right stakeholder involvement is critical and needs to include technical, heads of service, legal and regulatory representation to make decisions. It's important to strike a balance between creating an entirely new forum and reusing existing governance bodies with most of the right representation to take on responsibility for making collaborative decisions about social care data use. The body should have a mandate to act, agreed by partners from across social care.
15	Engaging the Welsh people and those with lived experience is critical.	Providing a balanced and representative view of Welsh people, including those with lived experience, about how data can and should be used to support them and their outcomes, is crucial for any effective data sharing collaboration. National Data Privacy Legislation and advisory bodies have increasingly focused on citizen engagement and co-design about how to use their own data to prepare and accelerate expanded or new data sharing initiatives.	Investing in a long-term capability to engage and gather Welsh residents' views and attitudes, especially those with lived experience about the use of their data, to drive care outcomes from a position of value to them is increasingly important. This evidenced perspective is needed to help drive the conversation in Wales about using social care data more effectively to improve outcomes and experiences for Welsh people.
16	Create the right information governance (IG) and ethics support.	A problem solving-based IG and ethics capability is critical to determining if information sharing paths exist and to help complete the work needed to follow them. This type of function, combined with a coaching ethos, can go a long way to building proportional data sharing solutions quickly, while making sure it's legal and regulatory.	Consider creating an IG review and decision-making body for social care that can be tasked with finding information sharing paths, if they exist, for strategic data sharing opportunities and advise on when initiatives should not be carried out.

Next steps

- Work with colleagues in local authorities, Welsh Government, CIW and DHCW to establish the scope and boundaries for developing common data standards in health and care.
- Use existing programmes of work, such as the NDR programme, to promote data standardisation in social care.
- Identify small, achievable projects to kick off this work and create the momentum needed for longer term ambitions.
- Assess whether existing good practice can be scaled up across Wales.

02

Developing roles and competencies for social care analysts

Background

Evidence from social care across Wales shows a lack of uniformity in analytical skills and capacity. Local authorities manage their analytics and data capacity very differently and some local authorities reported significant challenges in recruiting and retaining people in data and analytics roles.

This quick win looked at the use of new data sources to understand the market for analytical capability across health and social care in Wales. We gathered information about the analytical skills in social care. We combined this with information about analytical roles in health and care across the UK to develop our understanding of analytical roles in health and care in Wales.

This work will help with understanding the current and future requirements for relevant skills for analytical services in social care. It will underpin the objectives of the Strategic Statement of Intent, while giving further evidence from the market to provide consistency and clarity for recruitment and the development of analytical capabilities.

What are the desired outcomes of this quick win?

- **To test the value of new data sources to supplement our understanding of social care**
- **To establish a baseline of skills for analytical roles across care.**

Method

①

Big data analysis using millions of CVs and job adverts to understand which roles and skills are important to our current and future state of social care

②

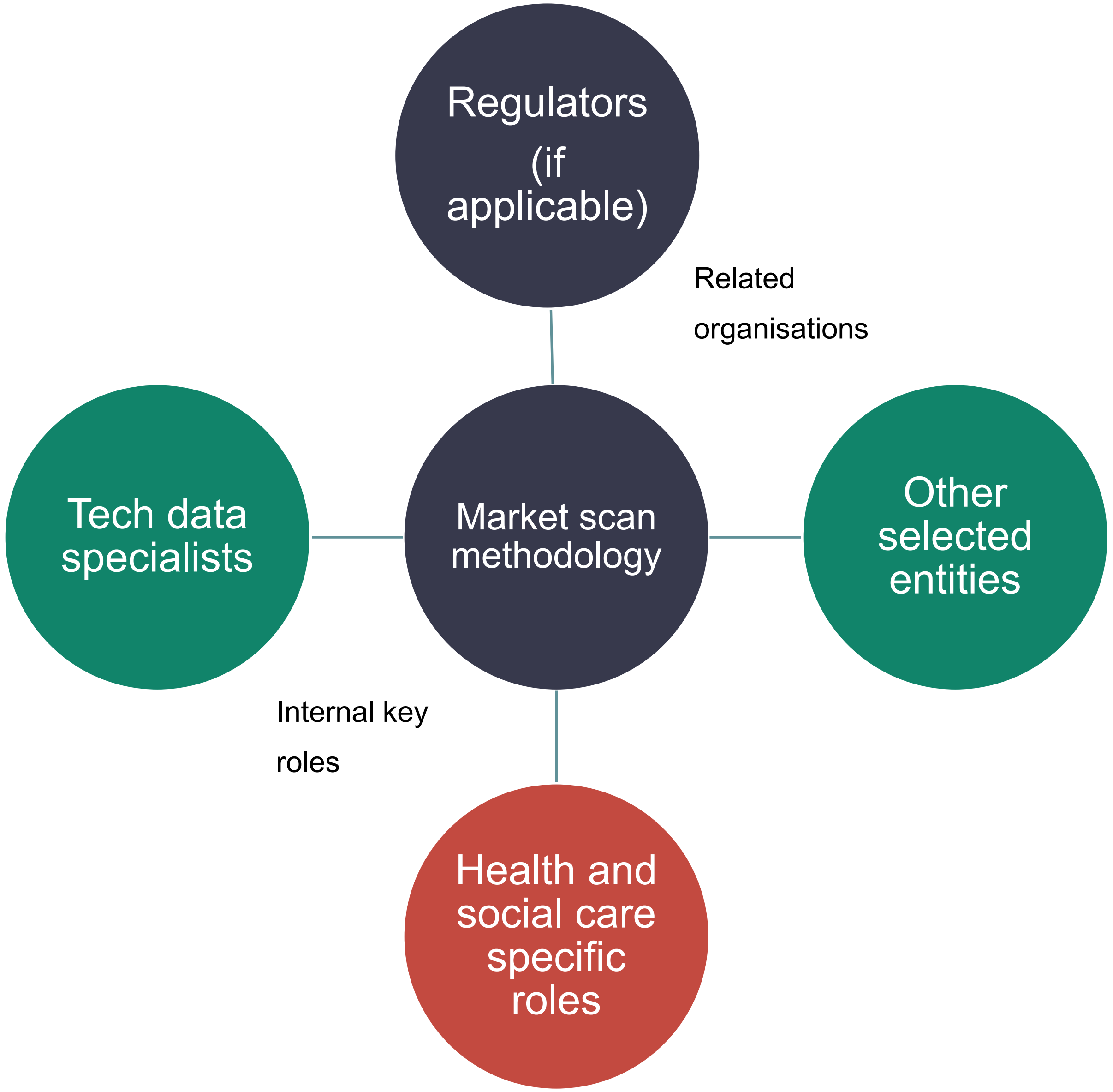
Map to existing occupation standards. These data are mapped to national and international occupational standards (see page 17) in the care sector and related areas

③

Validation of capability matrix

Scanning the market

- Performance analysts
- Health economics
- Informatics
- Health analytics
- Policy analysis
- Statistician
- Data scientists
- Data engineers



Regulators (if applicable)

Related organisations

Tech data specialists

Market scan methodology

Other selected entities

Internal key roles

Health and social care specific roles

Our market scan approach considered data specialist roles in relevant organisations, plus jobs such as policy, economics and other analytical roles.

The market scan also considered related organisations that recruit similar roles, such as regulators. We have reviewed the labour market demand from CVs and job adverts in Wales and the rest of the UK comparing health, social care and wider analytics roles.

Skills match

It’s important to identify the range of skills and levels needed to support the analytical capability for social care in Wales. This framework of skills can be informed by existing frameworks and aligned to the existing skills within the sector. Job descriptions can then be generated from them in a clear, cohesive and consistent manner.

These frameworks include:

DDaT

- Digital, Data and Technology Framework – developed from the Skills Framework for the Information Age (SFIA) and adopted by the Civil Service and other organisations.

SFIA

- Global skills and competence framework for a digital world. The BCS (Chartered institute for IT) has developed a proprietary *SFIAplus* with additional training and development resources.

APHA

- A healthcare focused analyst community.

FEDIP

- The Federation of Informatics Professionals in the USA.

AHIMA

- American Health Information Management Association – strong capability framework and career map in the USA.

NHS Job Profiles

- Current framework for information and analytics job specifications for NHS staff.

What we learned (1)

- There is little social care data-specific recruitment compared to healthcare and wider data analytics recruitment. Focusing on developing the social care workforce could support innovation and provide real value in a relatively underdeveloped area.
- Healthcare has formal job profiles defined and available on http://nhsemployers.org/. Unlike in social care, job adverts in Wales appear to follow standard job specifications and use the relevant pay bands.
- The analysis identified nine role clusters with 15 capabilities to inform and standardise analytical roles in social care (these are included in the full report).
- The proportion of analytics roles in health and care in England and Scotland is two to three per cent, compared to 10 per cent of analytics roles in Wales. This presents an opportunity to encourage students in universities to consider health and care analytics as a profession, rather than traditional IT career pathways.
- The analytical roles in social care were often administrative roles looking at 'performance management' and statutory reporting rather than data science or roles that are dependent on highly skilled individuals with an education in STEM subjects at degree level and above. Roles were far more diverse in health than in social care.
- Roles in social care were also far more likely to include a range of responsibilities that would each form a specific role elsewhere, such as project management, business support, business analysis or systems development.
- There are fewer opportunities for analysts and analytical roles in social care compared to health. The analysis identified health roles in relation to analytics, but social care roles were much rarer.
- We didn't find advertising for the most technical roles in social care (data architect, data engineer, data scientist). This could be due to this expertise being shared between departments or bought in through consultants.

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What we learned (2)

- Social care roles focus on performance analysts and management information roles, including compliance and data quality centralised in head offices (sometimes outside Wales for private care providers or provided through shared services within a local authority).
- Healthcare job descriptions had a greater emphasis on programming, research, policies and governance but less of an emphasis on data modelling, business and advanced analytics and visualisation.
- Candidates for jobs often have either a technical or managerial focus, but job adverts often require both sets of skill at high level, which will put off many candidates or raise salary expectations. Technical skills are given less emphasis and for councils appear to be low-level such as Word, Excel, Access, SQL, Business Objects.
- Some job descriptions require experience of specific tools or systems rather than more general competencies and there was limited reference to modern enabling tools such as self-service, dashboards or real-time alerts.
- Analysis of the data (including the job descriptions provided by local authorities in Wales) also produced other areas of insight into social care roles and recruitment:
    - Salaries for entry level Data/Information/Performance Analysts are £24,907
    - Job adverts are often long (12+ pages for health) and repetitive
    - Deliverables and responsibilities are listed but not prioritised so it’s not clear what the main tasks are
    - Deliverables and responsibilities often appear to be departmental and not role specific
    - Jargon is commonly used, including unexplained acronyms and terminology.

Next steps

- Assess existing professional development frameworks for their suitability for use in social care.
- Work with local authorities to assess their current capacity and capability in data and analysis skills and their use of data to inform decision making.
- Work with partners in Digital Health and Care Wales, Welsh Government, universities and other organisations to develop a skills development framework for data and analysis in health and care. The framework should cover basic data literacy skills for the entire workforce, as well as form a skills development framework for data analysis, using data in research, through to high-level skills in data science, machine learning and AI.
- Consider developing a skills certification programme for data analysts and data scientists in health and care.
- Develop innovative learning pathways for people and organisations seeking to improve their skills in data analysis and data science.
- Explore new mechanisms that allow local authorities and providers to improve their data skills, using resources such as the ONS Data Science Campus, apprenticeships and post-graduate sponsorship.
- Create common skills requirements that are portable across health, social care and other public sector organisations.
- Consider creating standard job descriptions for data and analysis roles that can be used by local authorities and other organisations as the basis to recruit and develop their own analysts.
- Work with colleges and universities to develop placements, sponsorship schemes and opportunities for graduate and post-graduate schemes that can fulfil the needs of social care improvement and development through the use of data and analysis.
- Work to further develop the collection and use of high-quality social care data in research and evidence development, particularly in a Wales context.

03

Citizen and practitioner enagagement

Background

This quick win set out to develop principles for co-design and engagement with the public and people with lived experience throughout the data strategy programme. It was done by:

- **carrying out desk-based research to understand what types of engagement are happening in Wales and the UK in care, and what has worked**
- **desk-based research to provide an understanding of what the sector already knows about data through engagement (for example, Measuring the Mountain) and where the gaps are**
- **developing the principles of involvement and designing an approach for citizen and practitioner engagement in the data strategy (for example, having a citizen challenge group).**

Why is this important?

We believe the programme will have more impact if it's driven by and co-designed with people with lived experience, their carers, and care workers. The Statement of Strategic Intent published in March 2021 identifies the importance for Wales to demonstrate what a data-rich nation can achieve for its citizens. It also establishes the ambition for collaboration and co-design, and the need for effective engagement with the people of Wales to achieve this.

Methods

In our first workshop, we shared and discussed user stories gathered from phase one with representatives from across the care sector. Our aim was to:

- **collect views about how people receiving care and providing care think about data**
- **identify their main challenges**
- **discuss how we could better support them through better data sharing.**

We also wanted to find out who we should talk to, and the best way to engage them about the topic of data. The insight from this initial workshop was incredibly helpful, even though it wasn't possible to include people with lived experience due to availability and timescales.

People shared thoughts and stories as follows:

> Real people don't think they have 'data'. They have stories. Stories about their lives, stories about themselves and others. We need to find a way of recording those stories to help support them.

> We need to be able to own our care plans. People need to be involved in developing and shaping their care and support plans.

> We owe it to the vulnerable children we support to hold their stories and manage them in a way that is useful and meaningful to them. Until we can hand that story over, it's our job to make sure that the data is used well.

> Everyone involved with a person receiving care is a contributor to care and support for that person at the centre. The lead professional is not necessarily the gatekeeper of the data. Providers of care often undervalue the contribution of the data they have access to.

Challenges

How can data sharing help people using and providing care and support?

The critical part of the care journey must revolve around making sure the person is at the heart of all data-sharing decisions being made.

It's essential people have a clear understanding about how their data is used. They should be able to control and co-produce their stories and ultimately own their personal care journey. This is key in building a better, more supportive care system.

Below we have indicated how better data can meet four of the main challenges.

Repeating a person's history again and again to new providers of care within the current system is frustrating, time consuming and stressful.	Better data sharing across all care providers allows people receiving care to have a more 'seamless' transition when care changes. The ability to easily share historical care requirements, key family contacts, likes and dislikes will save time and help new carers and care workers provide more tailored and sympathetic care and support. However, it's important to remember that not *all* people want to share *all* their data.
People with lived experience and those who support them aren't always given the right amount of support when a life change happens… "when the person I care for left the hospital I was just handed a big bag of pills! No instructions and I had to find it out myself".	With better data sharing between health and care, it will be easier to access a holistic view of the patient. Carers and care workers will be able to better understand the new/temporary care requirements of their patients and adjust their services to support them, helping them stay healthy and well.
Care plans are often generic and not that personalised or open to be validated by the receiver of that care "they need to be responsive and spontaneous", sometimes information that is considered "informal" doesn't make it onto a care record but "it's an important part of someone's story".	A common understanding of the types of data that are recorded and shared both with people who use or provide care and support will allow for a more flexible approach to service provision, through a greater understanding of the variability in the needs of the individual. It's important to understand the benefits and uses of the data.
Children and families are often concerned about how their stories are curated. We hear the data that's held is not in their voice, and they don't have control over it.	Better data sharing with people and their families (where appropriate) will enable people to have more of a say on how they interact with care and support, allowing them to shape their own "data" stories and own those stories by giving them more visibility of their care journey. Clear standards for how data is recorded and stored will help practitioners record consistently

What we learned

Our conversations to date have identified suggestions for what we need to start doing to improve outcomes for people who use care and support, and care providers.

We have identified a number of current ‘blockers’ (perceived or real). These might be cultural, or technology based. There are some ‘blockers’ that apply across the whole health and care system.

Lack of knowledge	• Fears in social care around data sharing, and a misunderstanding of what can be shared • People with lived experience can be worried about how their data is shared and the boundaries of data sharing • There are some concerns for frontline staff around formally recording what care and support they provide “out of fear of being told to stick to the care plan”
Presentation	• The way data is presented is often ‘about’ the person but does not involve the person in its development
Governance	• The right information isn’t always being captured in the first place
Confidence that data can help	• There aren’t many ‘good stories’ around data sharing. The stories that are heard focus on the risks rather than the benefits and opportunities
Data quality	• Lack of consistency in data standards • Some of the systems used to store records are older systems that don’t easily allow data sharing
Data sharing	• People don’t have access to the right systems to record data, for example, practitioners can’t easily record qualitative data • There is poor data linking across systems. Even once there is a record, it’s still difficult to gain a view of the whole person

Barriers to engagement

When we have reviewed previous data programmes and spoken to some of the people affected by them, we have identified some negative issues that we should be aware of as we design new programmes. These are relevant across the workforce and people with lived experience.

Digital inclusion: how the ‘data divide’ may create barriers to inclusion

Our initiatives need to build inclusivity as we need to make sure that people are not disadvantaged if they don’t want to, or can’t engage through digital channels. However, past experiences suggest that good design allows for the barriers to be overcome. For example, the Measuring the Mountain project supplied IT equipment and gave those taking part training to use it.

Inclusion can’t be assumed and must be assessed throughout the programme.

Time commitments: for building relationships and trust

Learning from successful projects shows that good engagement and co-production takes time and requires dedicated resources. Building trust with participants is identified as a success factor.

Financial: how people will be compensated for involvement

Reviewing successful engagement has highlighted the importance of appropriately paying for involvement. This should also be a consideration for members of the workforce who wouldn’t normally be given paid time to take part. Universities have successfully provided payments, but this can be more challenging for other organisations due to the tax implications for participants.

Balancing views/interests: open and transparent decision making

A wide range of groups are supported across social care, and their needs, aspirations and experience vary (even within groups that may appear to have common interests). The overarching governance will need to be mindful to seek a balanced view.

Where engagement works well

We identified the following areas of best practice in Wales that we want to learn from, and build on:

Patients Know Best is a social enterprise and technology platform designed to bring together patient data from health and social care providers and the patient's own data into one secure personal health record. It uses an online portal, which gives patients instant access to their medical records.

Patients can access up-to-date information about treatments, medication, allergies and more from any device. This can be shared with different medical teams and carers. Patients can also access messages from clinicians, test results and so on. Patients Know Best is being implemented in Abertawe Bro Morgannwg University (ABMU) Health Board (for patients with diabetes and with heart failure, extending to COPD and Parkinson's) and Cardiff and Vale Health Board (for ENT patients).

The **James Lind Alliance (JLA)** seeks to bring together patients, carers and health and care workers to make sure everyone has an equal voice in setting research priorities for health and social care. We recently worked with Health and Care Research Wales in an expedited process, based on the JLA priority setting approach, to identify research priorities for care and support for older people.

Measuring the Mountain brought together a cross-section of people across Wales (not just those with lived experience). Although there aren't extensive data specific findings (this was not specifically within scope) there are areas to learn from. These include:

- participants were paid for their time and supplied with IT equipment
- online engagement was successful, and participants engaged well.

There was visible Ministerial support and sign up for next steps.

Office of National Statistics (ONS): The ONS has published research about public attitudes to data and data sharing. The public's views about the acceptability of the use of personal data for statistical and research purposes differ according to who is using the data and for what purpose. While three quarters of the public don't object to data being shared with ONS, around three quarters raised concerns about data sharing in general. However, public acceptability of the use of data is improved by:

- appropriate communication, in particular, knowing to what use the data will be put and what benefits will result
- making sure safeguards relating to security and privacy are in place and communicated effectively.

International insight

Internationally, data is commonly referred to as ‘the new gold’. As part of developing this quick win, we have identified the following learning points:

People don’t always understand what ‘governments’ collect and why, and their role in helping to secure it.

Different sources of data must be brought together. Providing these data in an ‘analysis-ready’ format, allowing statistical relationships or patterns to be derived is a key challenge.

The risk of potential harm resulting from access to data is tangible but low. The level of risk can be further lowered by effective governance mechanisms.

There have been attempts to understand population attitudes. These have revealed varied attitudes to privacy – these are not always well explored or articulated.

There has been a focus on ensuring practitioners can access relevant high-quality research.

We can work together for change

We want to make sure we understand the experiences, views and ideas of those using care and support, their carers and people working in care and support. We also want to work together to design solutions that address the needs of those using care and support, carers and people working in social care.

Our communities for consultation include:

Workforce	Anyone who works in social care and social work
Carers	These are people who give care, but in an unpaid capacity
People	Those people who receive care and support
Local authorities	These provide or organise care
Providers	Including SMEs from the independent and third sector

Wherever possible, we will use our existing engagement approach with local authorities, providers and other stakeholders to make best use of people's time and avoid duplication. These organisations have an important role to play as employers, as well as in creating, holding and analysing data.

Putting citizens at the heart of the programme

People often interact with care systems at key points in their life, and often in crisis. Making sure health and care is designed around the end user and those working in it is essential for providing a long lasting and integrated quality of care.

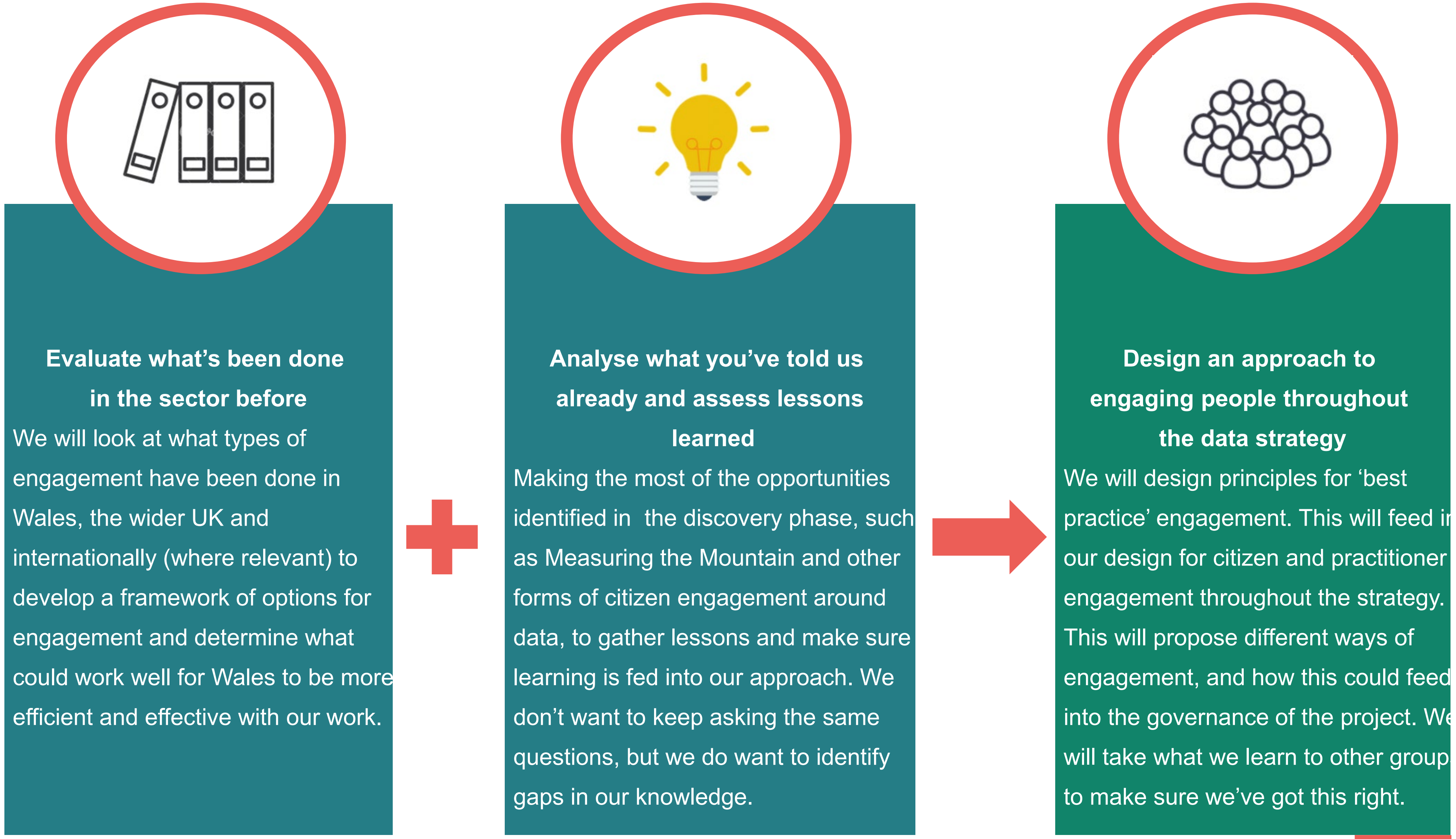
Experience has shown that designing from the outside in – through the lens of the patient/person or the employee – provides a stake in the ground for what's right. Human-centred design understands people's needs and expectations and puts those alongside practitioners across the user journey.

Our future approach

The first workshop identified that while data sharing is an important part of the data strategy engagement work, it's only one part of the puzzle. We're therefore focusing on developing an understanding of how we can engage people throughout the data strategy.

Consistent engagement with people with lived experience, carers, care workers and the wider public is essential in making sure people are consulted throughout the development and implementation of the data strategy, and that improving lives and service outcomes is at the heart of everything we do. Meaningful engagement is vital to show that input is valued and reflected in our actions.

This quick win will design an approach to engagement with citizens and practitioners throughout the data strategy.



Evaluate what's been done in the sector before

We will look at what types of engagement have been done in Wales, the wider UK and internationally (where relevant) to develop a framework of options for engagement and determine what could work well for Wales to be more efficient and effective with our work.

Analyse what you've told us already and assess lessons learned

Making the most of the opportunities identified in the discovery phase, such as Measuring the Mountain and other forms of citizen engagement around data, to gather lessons and make sure learning is fed into our approach. We don't want to keep asking the same questions, but we do want to identify gaps in our knowledge.

Design an approach to engaging people throughout the data strategy

We will design principles for 'best practice' engagement. This will feed i our design for citizen and practitioner engagement throughout the strategy. This will propose different ways of engagement, and how this could feed into the governance of the project. We will take what we learn to other group to make sure we've got this right.

Draft principles for engagement

Based on what we have learned so far, we propose the following principles for engagement in the ongoing programme:

We'll make sure that people who use care and support, their carers and care workers shape the programme. This isn't an add on, it's how we do things throughout the life of the programme.

We'll make sure that people who are involved in the programme are informed about and understand the outcome and impact of their involvement.

We'll make sure we listen to people who aren't always heard. We'll do this proactively, monitoring the engagement to make sure it's comprehensive.

We'll respect people's time and compensate them accordingly, making sure we build on previous experiences.

We'll promote and fund inclusive user-lead research and try to build capacity in the sector to undertake this.

We'll strive for continuous improvement and be open to changing our approach as needed through our inclusive governance. We know we won't get everything right at the outset.

Organisations across Wales have signed up to the public engagement principles created by WCVA, and we'll use these as a basis for our public engagement wcva.cymru/influencing/engagement/

Next steps

There isn’t a comprehensive baseline of what people with lived experience, their carers and care workers feel about data sharing. There are some insights that help us know where we might want to focus. However, there’s still a need to establish at a ‘population’ level what people think, feel and what they would like to prioritise. We will need to:

1. establish a baseline of attitudes
2. make sure the programme fully includes these groups.

- Create a stakeholder communications plan
- Engage and co-design with the public and people with lived experience
- Identify and carry out a deliberative, participative and democratic approach to engagement, such as citizens’ juries or assemblies
- Create a workforce data panel. Establish a baseline of practitioner views
- Build a good practice library for engaging meaningfully with citizens. Consider establishing a Social Care Wales Community of Practice for knowledge sharing and support

04

Enabling data sharing with SAIL and others

Background

What is this quick win about?

This quick win is about exploring ways to improve and encourage the sharing and linkage of local authority data with the SAIL Databank, and other key organisations.

Data linkage, or record linkage, is the process of identifying, matching and merging records from multiple datasets that correspond to the same person or identity.

When sharing data, it can be difficult to link an individual across multiple data sets – particularly if it's anonymised. Data linkage tackles this challenge, enriching the depth of data and enabling more powerful insight.

Why is it important?

Sharing and linking data between organisations opens up new research opportunities and strengthens the conclusions drawn from the data.

This allows organisations to leverage the value of each other's data, improving insight into 'what works' and how to enhance the quality of services.

Supporting data linkage involves giving confidence to citizens that their personal information is kept secure.

Our discovery phase identified improving local authority data sharing and linkage as a potential area of focus for a quick win. More recent conversations with a range of stakeholders suggests there may be other areas to explore.

What are the desired outcomes of this quick win?

To communicate the benefits of data sharing and encourage organisations to work together to maximise the data available for researchers and analysts

To streamline data sharing and information governance processes, reducing costs and improving efficiency

To make a tangible improvement to the ease with which organisations gathering, using and analysing social care data can create linkages between shared datasets

To provide valuable analysis and insight to those who share their data

How will this quick win achieve this?

- Exploring digitising data sharing agreements and Data Protection Impact Assessments (DPIAs)
- Exploring reducing barriers to local authority data sharing with SAIL and how to support data linkage
- Identifying and accelerating other ongoing work in this space

Sharing operational insight

Feedback from discussions with local authorities suggested that encouragement and incentives would improve the frequency and volume of data sharing with SAIL.

One incentive might be to offer local authorities visibility and analysis of the data sets to which they contribute, potentially in the form of dashboards.

Step 1
Periodically, local authorities upload data relating to the data set in question, covering the latest period.
The uploaded data conforms to a standard template and is uploaded using SAIL’s standard approach.

Step 2
SAIL receives and processes the uploaded data.
A dashboard driven by this data is refreshed when all data is received for the given dataset and period.

Step 3
Approved users from each local authority have permissions to access the dashboard.
Visibility of the dashboard is restricted to the local authorities that regularly contribute their data.

Outreach and communicating the benefits of sharing

A potential barrier to sharing data with SAIL relates to concerns around data sharing, and understanding of who SAIL is, what it does, how to engage with it and what the benefits are.

To overcome these barriers, we recommend a focused exercise to share information with local authorities about data sharing and SAIL, and longer-term efforts to make data recommendations here include ideas from a workshop held in March 2021.

It’s likely that authorities have concerns and questions around data sharing, for example:

Why should I do it?

How do I do it?

Who do I do it with?

Is it secure?

Who is SAIL?

What does it do?

What do I get?

What we learned (1)

Enablers

- SAIL has produced notable research findings, such as Born into Care (www.nuffieldfjo.org.uk/resource/born-into-care-wales), a report on mothers and babies who come into care proceedings. There's growing awareness that data linkage is possible and offers an opportunity for new insights.
- Participants in meetings and workshops indicate that sharing is viewed as a good thing that is to be encouraged, and that this perspective is held among senior stakeholders and decision makers.
- Getting data in the correct format takes time but once done it's easy to upload to SAIL.

Challenges

- Information Governance (IG) documentation is the single biggest blocker identified, as it's complex, difficult to complete and time consuming.
- There are too many IG agreement templates in use. This increases complexity, uncertainty, risk and the amount of time it takes to process agreements.
- Internal sign-offs are challenging. Multiple sign-offs are required, which means many stakeholders with a range of views or concerns might need to be convinced.
- Security concerns are a factor, particularly where any technology interfaces with local authority servers.
- Data quality is a concern. The data being shared must be of high enough quality to reflect the realities on the ground, and understood by researchers using it in other contexts. Some fundamental facts (such as the number of unpaid carers in an area) can be difficult to identify, depending on how this information is held in systems and might be done in different ways in different local authorities, making direct comparisons more challenging.

What we learned (2)

Engagement

- Staff buy-in is important to maintaining data quality.
- The burden of data input is high, but the value or impact isn’t obvious to the frontline staff doing it.
- Those consuming data downstream, including SAIL, could do more outreach to raise awareness of this value.
- We understand there’s a growing awareness of SAIL, but it’s still not widely known. It’s not immediately obvious to non-data specialists what SAIL does or its value when they try to engage (for example, by exploring the website).

Accessibility

- There was a perception that SAIL obtains information and data but it can be hard for those in local authorities to get anything back in return.
- There was a concern that while SAIL can make important comparisons between local authorities, this might be challenging for some, where it reveals differences in performance.

Potentially useful operational insight from SAIL

- Connecting other data sources (such as benefits information or GP data) to identify those who are carers but unknown to the local authority to:
    - identify geographical areas where carers are less served
    - identify conditions or health and well-being needs that are currently not met.

Next steps

Opportunities for improvement

Using feedback from local authority representatives, we have identified opportunities for work to tackle barriers for sharing local authority data with SAIL. We recommend adopting a partnership approach. Involving appropriate organisations, and earning their support, is key to resourcing and driving success.

	Opportunity	Brief description
1	Digitise manual, heavily paper-based information governance processes to allow faster and more trusted information sharing between care organisations.	A central digital platform would improve and modernise the administration and risk assessment of information sharing. This could drastically increase the number of agreements while cutting the risk management and administrative burden. It would empower organisations to share information across care boundaries in a way that the current paper-based systems simply can't.
2	SAIL, and other organisations where appropriate, to invest in a mechanism to share operational insight and datasets more easily with partners who share their own data.	Feedback indicates that there aren't many incentives for a local authority to share their data with SAIL. To give such an incentive, SAIL could consider offering something in return to encourage participation. This could take the form of analysis and insight publications or dashboards on various datasets. The insights would be relevant to operational teams on the frontline of care provision. These would only be accessible to those local authorities that contribute their data.
3	Outreach and communicating the benefits of sharing to local authorities.	Authorities that are less data-focused may be unaware of the benefits of data sharing, who SAIL is and what it can offer. We suggest reaching out to relevant leaders at each authority and giving them the guidance they need to understand the offering, to generate enthusiasm and engagement.

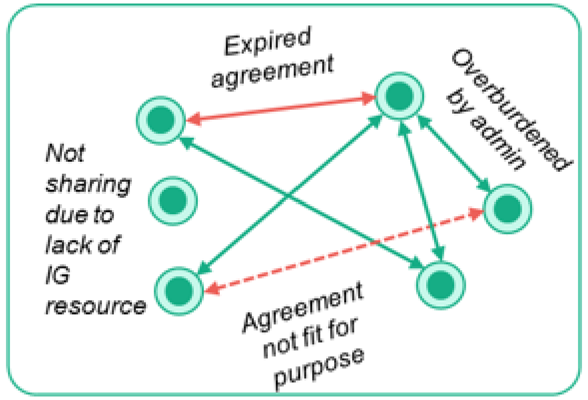
Piloting the information sharing gateway for Wales

Current challenges

Social Care organisations recognise the benefits of sharing information.

However, managing the flow of information between organisations through paper-based systems is extremely challenging:

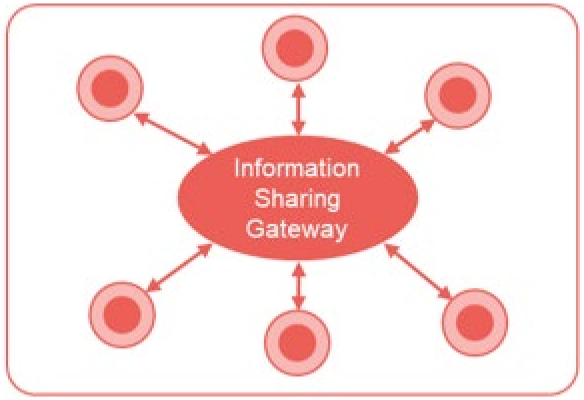
- **time consuming**
- **inflexible**
- **confusing**
- **laborious to track and sign agreements**
- **agreements tracked and managed manually through spreadsheets, paper agreements, Sharepoint, scanned signatures and so on.**



The opportunity

An information sharing gateway would support electronic information sharing across care boundaries in Wales:

- **storing all information related to sharing in one place**
- **common rules about information sharing**
- **mapping of data flows all in one place**
- **automation of processes**
- **automated monitoring, such as alerts when agreements expire**
- **technical support for users.**



Benefits

- **improved sharing** – unlock the benefits of more sharing
- **compliance** – lower the risk of not meeting regulatory demands
- **reduced time and cost** – much faster and cheaper than a paper-based approach
- **confidence** – that data protection regulations are being met
- **transparency** – understand where sharing is taking place and any requirements
- **trust** – in each other's information governance
- **efficiency** – remove paper from the process and do more with less effort
- **consistency** – move towards a single consistent set of template agreements that are widely understood. This lowers any perception of risk and makes agreements easier to process
- **automation** – for example, inform users when agreements are expiring to reduce the risk of non-compliance, and digital sign-offs, which make it easier to reach decision makers.

05

Developing social care workforce data

Background

This quick win focuses on how a new approach to collecting social care workforce data can be used to share new types of insight across the sector. This discovery phase specifically identified the potential to make greater use of the workforce data we collected by sharing it back to local authorities through the National Social Care Data Portal for Wales.

What is this quick win about?

We are introducing a new approach to collecting social care workforce data from local authorities and social care service providers. Mandated by Welsh Government as part of the new *Performance Improvement Framework*, this new system aims to make it more streamlined and improve the quality of the data being returned.

This data will be collected annually with regular updates to the relevant dashboards published on the National Social Care Data Portal.

Why is it important?

The output is an example of identifying useful social care data and making it available:

- showcasing the 'quick win' methodology – identifying and implementing clear, actionable opportunities to change how data is used for the better
- role modelling the behaviours the data strategy hopes to encourage, around proactively identifying and sharing data that others may find useful
- showing the potential value of building and incrementally improving data tools, to benefit partners across social care.

What are the desired outcomes of this quick win?

Local authorities and workforce planners are able to leverage workforce data for comparative insights that support their workforce planning.

Other users are able to explore the data for their purposes and identify further use case opportunities.

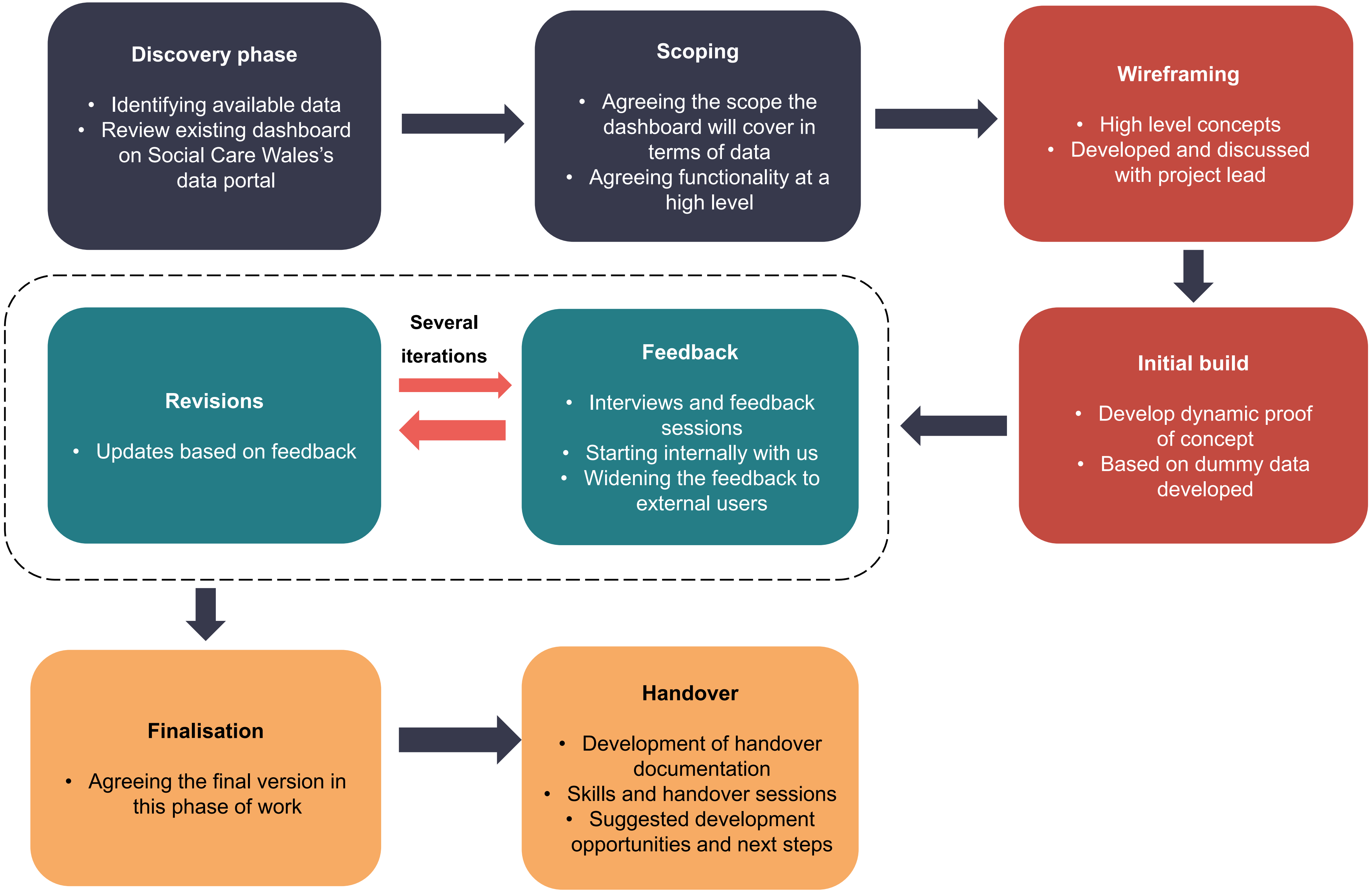
Demonstrate that the National Social Care Data Portal for Wales can be used to share data in new ways.

Social Care Wales analysts own the product, understand it and iterate it going forward, potentially using this as a stepping stone towards creating other dashboards in future.

How will this quick win achieve this?

- Produce a proof of concept dashboard that can accept workforce data, when received, and be published on the National Social Care Data Portal for Wales.
- Supporting documentation, handover notes and skills sessions all provided to analysts owning the dashboard in future.
- Recommendations for next steps and further development opportunities also provided, to enhance the dashboard and the underlying database.

Dashboard design - process



Discovery phase

- Identifying available data
- Review existing dashboard on Social Care Wales's data portal

Scoping

- Agreeing the scope the dashboard will cover in terms of data
- Agreeing functionality at a high level

Wireframing

- High level concepts
- Developed and discussed with project lead

Initial build

- Develop dynamic proof of concept
- Based on dummy data developed

Feedback

- Interviews and feedback sessions
- Starting internally with us
- Widening the feedback to external users

Several iterations

Revisions

- Updates based on feedback

Finalisation

- Agreeing the final version in this phase of work

Handover

- Development of handover documentation
- Skills and handover sessions
- Suggested development opportunities and next steps

What we learned

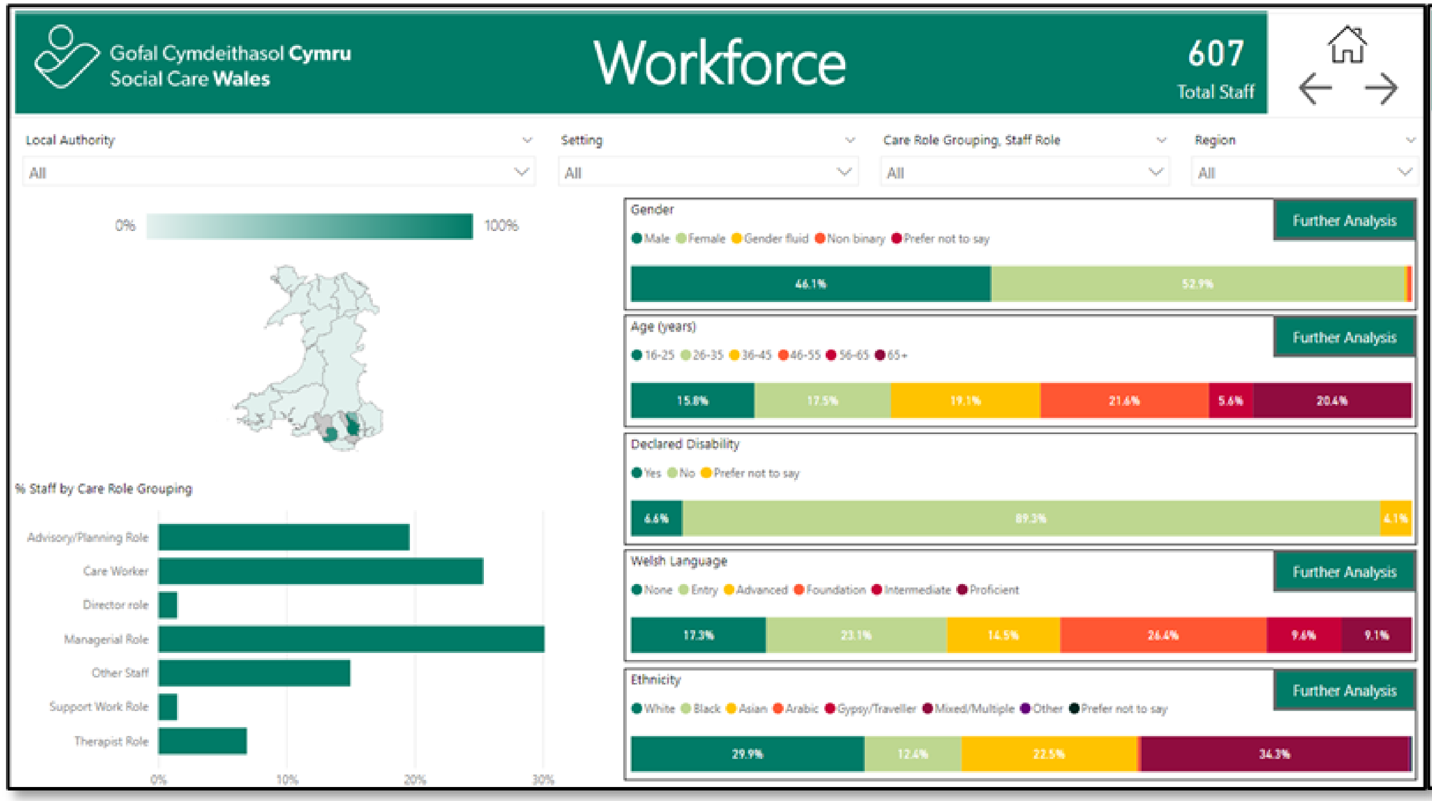
During this process we noted several recommendations and further development opportunities. These are:

1. Change from Power BI dashboard to Power BI app:
    - can be converted on the Power BI workspace, once the dashboard has been published
    - to convert the dashboard to an app, appropriate licensing is required on the Power BI workspace.

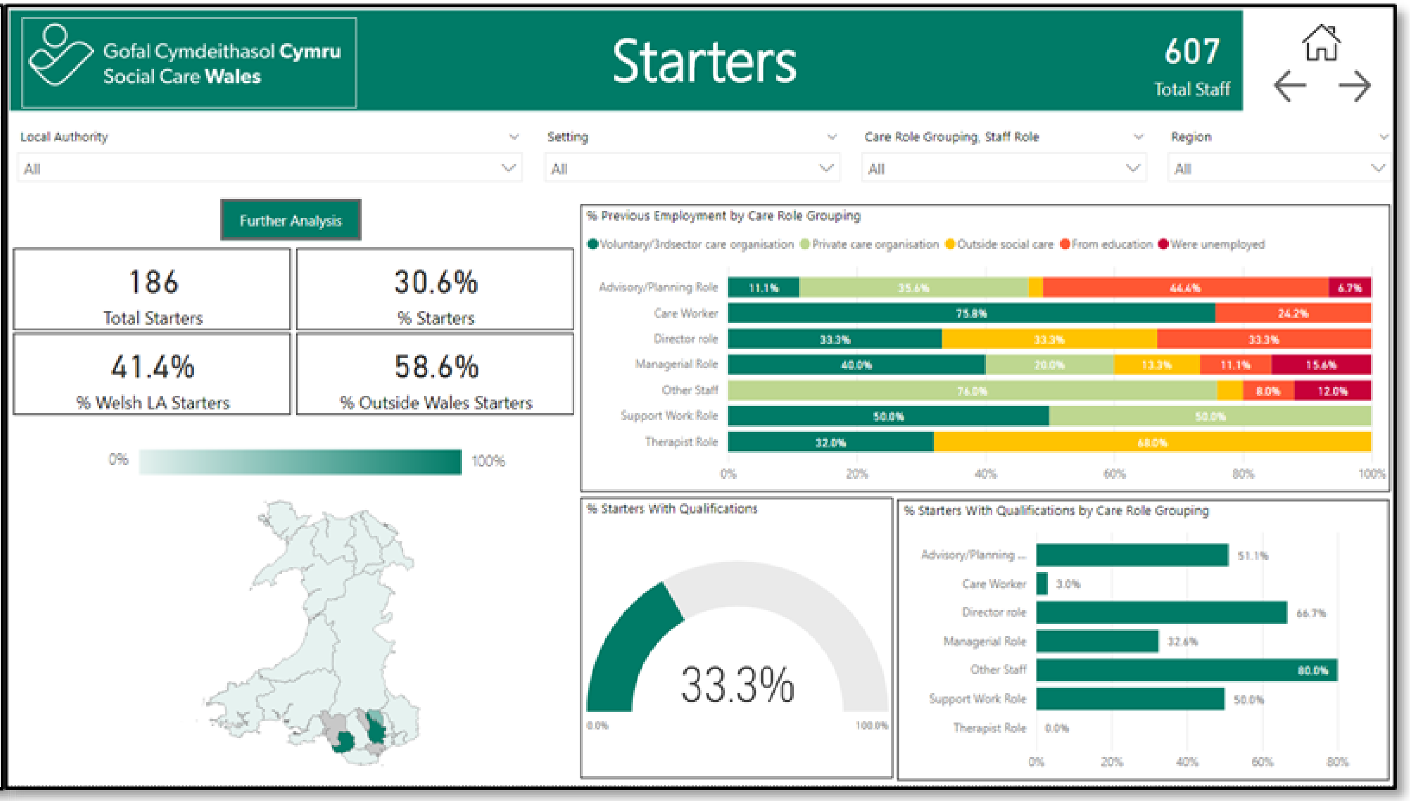
2. Align colour theme, backgrounds and page settings to match our dashboards.

3. Use of hyperlinks:
    - open data once collection has finished
    - provide workforce definitions in the dashboard for clarity.

Sample dashboard views



Local Authority: All
Setting: All
Care Role Grouping, Staff Role: All
Region: All



Local Authority: All
Setting: All
Care Role Grouping, Staff Role: All
Region: All

Next steps

We identified other development opportunities:

- use our other data sources or expand the current collection to create new measures and further analysis:
    - employee tenure
    - reason for leaving the company
    - time between promotions
    - pay analysis
    - deep dive into qualifications such as apprenticeships
- use previous workforce data to allow some level of comparison
- once further data collections have taken place, create year-on-year comparisons and measures of change
- work towards publishing the workforce data as official statistics by following UK Statistics Authority code of practice.

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Other formats: This document is available in large text or other formats, if required. Copies are also available in Welsh.