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

# A strategic approach to social care data in Wales

## Report on the discovery phase

November 2020

> **Nerth gwlad, ei gwybodaeth**
> The strength of a nation is its knowledge

# Contents

# Foreword

Making use of high quality, robust data that is accurate, reliable and accessible to citizens and professionals is key to delivering social care over the next decade. It has the ability to transform the way we use services. It allows us as citizens to choose how we share our information and with whom we share it and allows the right information to be available to the right people at the right time, making sure that we achieve the very best outcomes for people who need care and support and carers who need support.

The use of data allows us to improve the way we are able to provide people care and support in a secure and responsible way. Combining the use of data with the latest and most accurate research and evidence is vital so that we are certain that we are making the most appropriate and informed decisions. It informs the decisions that we make every day as social care practitioners and informs the future direction of social care in Wales.

The COVID-19 pandemic has demonstrated clearly that data, research and evidence is of paramount importance in informing our decision making and our direction of travel at every level of the sector. Across Wales, the UK and the world, we have seen a huge increase in our reliance on statistics, scientific evidence and research. This increased use of data and research evidence has helped us to understand and navigate our way through the most significant international crisis that we have collectively experienced during our careers in social care.

I set out my intention for this data strategy long before the start of the Coronavirus pandemic. In September 2019 I gave my annual address at the ADSS Cymru National Social Care Conference. In this speech I set out my vision for social care data in Wales and announced my intention that a National Social Care Data Strategy would be developed. I invited Social Care Wales to take the lead on the development of this strategy, in partnership with Welsh Government and the NHS Wales Informatics Service.

I am very pleased to see that the discovery phase of this work is now complete and is set out in this report. It is clear that there is much to be done, but I am reassured by the engagement from across the sector in shaping this important piece of work and look forward to us continuing to work together as the data strategy develops.

I want Wales to become a data rich nation, able to make the best use of this valuable asset in delivering the highest quality care and support and support for carers– and this is our first important step in achieving that goal.

**Albert Heaney**

Deputy Director General for
Health and Social Care

# A note to our readers

Dear Reader,

A Healthier Wales is a long term plan to bring health and social care services closer together, so they are designed and delivered around the needs of individuals. The plan has a much greater emphasis on keeping people healthy and well. To deliver this ambition we need to value and use data about services better. This includes how we make data available to citizens to manage their own care and support; how we support community groups, care workers and social workers to deliver care and support services.

This scoping report has shown how difficult it can be to get hold of the data we need to plan and deliver care and support services in Wales. People do not always have access to the data they need to do their job effectively. This makes it difficult for social care to be better aligned with health and other services. We know a lot of change is already happening and we need to do more.

We need to change how we work, to collect meaningful data, use data better and encourage data sharing between organisations, to provide better services to those people who use care and support services.

This scoping report looked at the ways in which we currently work, our ambitions, our challenges and the opportunities we have to make better use of social care and social services data in Wales. It suggests a consistent approach with easier access to data across Wales to help the people of Wales to live the lives that matter to them.

This report has been produced by Social Care Wales in collaboration with the National Data Resource Programme and NHS Wales Informatics Service, with support from the Welsh Government.

We held discussions with 42 stakeholders from at least 27 organisations.

Public bodies (local, regional and national), third sector organisations, working groups and individuals with lived experience of social care have all contributed their perspectives.

We would like to thank everyone who contributed to this report. We really could not have done it without you.

We hope that you'll help us shape the journey to support the ambitions we have all set out in this report. We want to help people make more informed choices about the services they receive, by sharing information about their health and care and working in partnership to coordinate the care and treatment people need, so that it is delivered seamlessly.

**Sue Evans**
Chief Executive, Social Care Wales

**Helen Thomas**
Interim Director, NHS Wales Informatics Service

# Executive summary

## What is this report?

This is a discovery report, produced in response to a requirement to scope the development of a data strategy to support social services and social care in Wales.

This report, following a rapid review of the existing data landscape, ambitions, challenges and opportunities, outlines a suggested approach to developing a national data strategy for social care.

This report has been produced by Social Care Wales in collaboration with NHS Wales Informatics Service, with support from Welsh Government.

## What does this report contain?

This report sets out:

- Background and context
- The approach used for the discovery phase
- Themes identified through the discovery exercise
- Principles for delivering a data strategy in Wales
- A vision and guiding principles
- Suggested next steps
- Appendices

## What should happen next?

This report sets out a methodology by which we propose to deliver a future data strategy.

In particular, we will concentrate on use cases to identify, agree and coordinate effective workstreams that respond to the requirements of citizens, people who use care and support, and professionals.

## What decision is required?

This report outlines a suggested way forward with three strands:

- Strand 1: a statement of strategic intent
- Strand 2: a future roadmap
- Strand 3: quick wins

Each strand includes an overview of the work required, although the roadmap will need developing more fully in due course.

# Background and context

# An unprecedented opportunity

Across the social care sector, social care staff and local authorities have always played a vital role in supporting our communities. In the wake of COVID-19, the importance of the social care sector has never been clearer or more recognised.

Communities, social care workers, and users of social care services have endured lasting budgetary pressures. Early in the coronavirus outbreak, it became clear that the use of social care data, too, lacks equity and maturity. It is much more difficult than it should be to gather and access the data we need to deliver care and support to the people of Wales.

> **"[COVID-19 showed that] when the chips are down, the barriers we've created [to sharing data] don't mean anything."** – Welsh Government stakeholder

This journey has already begun. In 2014, concrete legislative steps were taken to address the inconsistencies in care across Wales and move to improve service outcomes through the Social Services and Well-being Act. The legislation and initiatives undertaken provide the basis for investing in our care services, to enable our residents to live happier, healthier and more independent lives.

Health and social care are rapidly evolving in Wales. There is growing awareness that in order to serve people and communities effectively into the future, every organisation involved will need to invest in insight to allow services to become more outcome-focused, holistic and collaborative. Transparent, accountable, evidence-driven decision making is best practice, and increasingly mandated by legislation and policy.

The wider care sector in Wales, whether social care or healthcare, has a unique opportunity to change the way it harnesses the power of social care data to best meet the needs of people and communities. By investing in data, we can build one seamless vision for health and social care across Wales.

# Social care in Wales

## The story so far

> **Nerth gwlad, ei gwybodaeth**
>
> – The strength of a nation is its knowledge

**The Welsh proverb above could have been written today.**

Over the last 10 years, the Welsh Government and partner organisations have made significant progress in evaluating and assessing the challenges faced by the social care sector.

Several strategies, frameworks and pieces of legislation have been developed since the **Social Services and Well-being (Wales) Act 2014**, to support improvement of health and social care services and integration of these services to provide **"one system of seamless health and care for Wales".**[1]

These include:

- **The Well-being of Future Generations (Wales) Act 2015:** outlines seven well-being goals that public bodies should work towards to improve the social, economic, environmental and cultural well-being of Wales
- **The Regulation and Inspection of Social Care (Wales) Act 2016:** sets out the regulation and inspection of social services departments and social care providers, with a requirement for them to make information available about services, performance and quality.
- **The Parliamentary Review of Health and Social Services (2018)[1]:** provides a comprehensive overview of challenges faced by the health and care sector
- **A Healthier Wales (2018):** sets out the vision and goals for an integrated health and care system, focusing on long, healthy, and happy lives
- **Performance and Improvement Framework (2020):** provides guidance for local authorities and partners surrounding measuring performance, as part of the implementation of the Social Services and Well-being Act.

Together, these and other laws and policies advocate for an integrated community of care practice across Wales. Underpinning this vision is an understanding that, in order to provide high quality services and ensure that care is being delivered efficiently and effectively, evidence-based decision-making is essential.

**In future, however, the use of data must move beyond health and social care to include other dimensions such as education, housing, leisure, socioeconomic factors, and more. These factors help to drive demand for health and care services.**

By investing in the consistent collection, management and analysis of data across Wales, we will be able to help public bodies make the most of their rich data assets and use their insights to drive change and growth in Wales, providing high quality personalised care in our communities.

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[1] A Revolution from Within: Transforming Health and Care in Wales – final report, 2018

# What is social care data?

**Social care data is, at heart, about the story of a person experiencing one or more social care services.**

In social care, people are more than just numbers. Organisations that provide social care services collect information partly because they are required to do so by regulators and Welsh Government, but also because it helps them to understand the people experiencing their services, their families, and their wider communities.

For the purposes of this report, social care data is considered to refer to any information collected in the course of providing a social care service, or in preparation for doing so. It could be complemented and supported by non-social care data, such as data about education, health, housing, or services provided by third sector organisations.

Social care data is widely used throughout Wales. People and organisations which use social care include the following:

- People who use care and support
- Members of the public
- Frontline workers
- Local authority leaders and managers
- Legislators
- Carers
- Community centres and groups
- Third sector and voluntary organisations
- Regulators and watchdogs
- Organisations delivering social care services on behalf of a local authority
- Independent researchers and academics

# The discovery approach

# Using a discovery phase approach

The design of this scoping exercise followed a discovery phase approach. **A discovery phase should be curious, informative consultative, inclusive, dynamic, and foundational.** The discovery model is becoming increasingly popular, and focuses on establishing a clear understanding of ambitions, risks and challenges and the current state of systems.

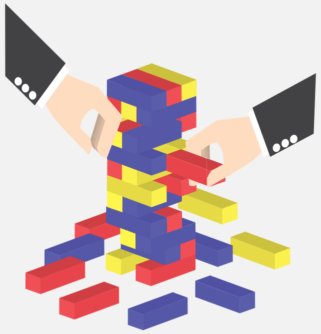
1

Identifying aims and aspirations

2

Address current key constraints and challenges

3



Highlight existing assets and opportunities available

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These phases are supported by both primary and secondary research. This model enables organisations to define a clear ‘problem statement’ and vision for data.

Stakeholder interviews

Document review

Review of legislation, policies and other materials

Stakeholder workshops

# Why a data strategy?

A data strategy aims to develop a single working vision of how data should be collected, managed, stored, analysed and finally utilised to bring about greatest potential benefit.

Below, we have set out some of the benefits to result from an effective data strategy. The categories used align to our best practice experience.

## Reporting and Analytics

- Insight products that allow data to tell stories, not simply measure compliance
- Real-time data for rapid decision-making
- Automation of manual tasks to free up capacity for both workers and data scientists
- Self-service for workers and managers, allowing them to see the data they need rapidly and easily

## Data Governance and Management

- Consistent data standards that all organisations share, with published definitions for each data item
- Organisations prioritise the quality of their data, using automatic tools to look for concerns and address them, so that the whole system benefits
- The whole system shares data appropriately and safely, identifying and mitigating risks and concerns
- Publishing data as official statistics inspires public confidence by demonstrating trustworthiness, enhancing public value with high-quality information

## Skills and Talent

- A social care system and workforce that understands the importance of data
- A shift from data analysis to data science, with a focus on the tools and training that enable this
- Recognising that not all skills can be recruited, for example by releasing open data where it’s safe to do so, allowing external experts to derive new insights

## Leadership and Culture

- Leaders who understand the value of data
- Governance and leadership arrangements that include senior data representation, such as a Head of Data or Chief Data Officer
- Collaboration across the system to pool data capabilities and resources where this can help to alleviate funding challenges
- Trust: accurate data, legal permission to use it, and support from leadership to do so

## Culture and Continuous Improvement

- An environment, supported by leaders, where data is nurtured and trusted
- Comparison and learning across Wales, driven by consistent standards and encouraged by pooling of resources
- An evidence-driven approach to services, first using data to make decisions and then building an evidence base to make the next decision easier

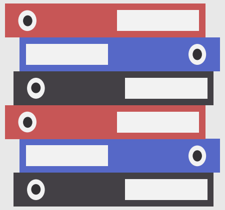
## Tools and Technology

- Basic data management and reporting tools that are easy to use and up to date
- Common platforms to allow data to flow from different systems into one place
- Investment in advanced analytics tools to build new capabilities such as working with unstructured text in case notes
- The use of digital platforms to encourage citizens to access services themselves

# Discovery themes

# Key themes: facts and soundbites

Around 30 organisations represented



**More than 20 documents reviewed**, including legislation, policy, case studies and plans

**42 people met**, representing a range of views, perspectives and motivations

**“’If we’d known this, we wouldn’t have done that.’”**

— Local authority, explaining how data helps

**“Where the system works well is where people are truly signed up [to the Well-being of Future Generations Act].”**

— Person with lived experience

**“[Sharing data creates a] ‘sharing your homework’ risk – what if I’m judged, what if I haven’t done it right or as expected?”**

— Third sector

**“People see it as another task, when it’s actually the most important task.”**

— Policymaker

**“Like pulling teeth.”**

— Several people recount their experience of trying to access or share data

**“What’s the point of having annual returns if there’s no standards?”**

— National commissioner

# Views from professionals and citizens

The interviews we conducted with stakeholders across the system (see **Appendices** for more details) have allowed us to develop a set of **personae**, shown below. These personae represent a generic viewpoint without being specific to the feedback of any single individual.

| | Current challenges | Implications of challenges |
|---|---|---|
| <br>Citizen | I rely on the worker I know, and they help me live my life on a day to day basis. But there is no continuity when a worker changes. **I often have to tell my whole story again, and I worry they might take away my services** if they don't see me as 'needy' enough.<br>If they saw me in the round, they would understand me better. | Without robust care records, it can be slower to spot and respond to safeguarding issues, and people's needs can be missed when case workers or circumstances change.<br>**The current system forces people to emphasise their needs, not their strengths, which can foster dependency and is not in line with Wales' ambitions.** |
| <br>Practitioner | I visit lots of people daily, all with different needs. I do more than just turn up and help – I listen. I know people's families and their communities.<br>**I have lots of important knowledge about people's stories, but I normally have to record it in case notes. I'm not sure anybody uses the data I record.** | Without a sense of how their data benefits planning and delivery of better services for people, **frontline workers may not prioritise timely and accurate recording**.<br>This can make it harder for workers to provide a consistent service to residents, especially where case workers change or services are very busy. |
| <br>Director of Social Services | **I want to know if our initiatives are actually making a difference but I don't have the capacity to measure them.** I provide the performance metrics in the Annual Report but I'm not sure we're using our resources effectively.<br>I try to use data to support our decisions, but it's difficult to see it in the round in a timely way. | Without utilising data, **it is difficult for local authorities to know they're making the right decisions about investment or services**.<br>This limits their ability to act preventatively, plan and budget effectively, and develop strong evidence bases to foster and target improvements. |

# Views from professionals and citizens (cont.)

| | Current challenges | Implications of challenges |
|---|---|---|
|  Data Analyst | I spend most of my time dealing with statutory data returns. A lot of the work I do is very repetitive and I feel like I'm just plugging the numbers into a spreadsheet.<br>**I collect so much data but I don't often have the time to use it to draw real, helpful insight in a way that everyone can understand.** | Without the right tools and skills, analysts may not be used to their full potential. Even with tools capable of automating reporting and distribution, time and investment is required before significant productivity gains are experienced.<br>**In the meantime, leaders find it difficult to access the insight they really need.** |
|  Regulator | I use data about social care to compare services so that I can measure effectiveness across the country.<br>**It's difficult to evaluate fairly, however, because there are no common data standards** – different areas measure different things in a different way, or sometimes data is missing altogether. | Without the standardisation of data definitions and collection across social care in Wales, **regulators are unable to effectively measure and compare quality of care**.<br>This inhibits the support they can provide to the system, and endangers the ambition for quality of care to be equal across Wales. |
|  Policymaker | Data tells me whether policies are effective or not, whether the care and health system as a whole is working as it should, and whether vulnerable people are being kept safe.<br>Although legislation like the Digital Economy Act provides cover for data sharing where it helps public services, **I don't see as much sharing as I expect, and partnership working on data is often missing.** | Since organisations across Wales don't use data to its full potential, **the use of data is often seen as punitive and negative. The desire not to be an outlier in the data encourages a 'race to the middle'.**<br>At the same time, confidence in the system is low since past data-related initiatives haven't worked as well as hoped. This means that trust is limited and alignment is challenging. |

# Workshops

**In addition to individual or group interviews, two workshops were held during June and July 2020.**

The first workshop brought together around 15 senior stakeholders across the social care system and beyond, and focused on reviewing a problem statement (**see page 34**) and a vision for the future strategy (**see page 36**). Attendees were also asked to consider opportunities and challenges it would face.

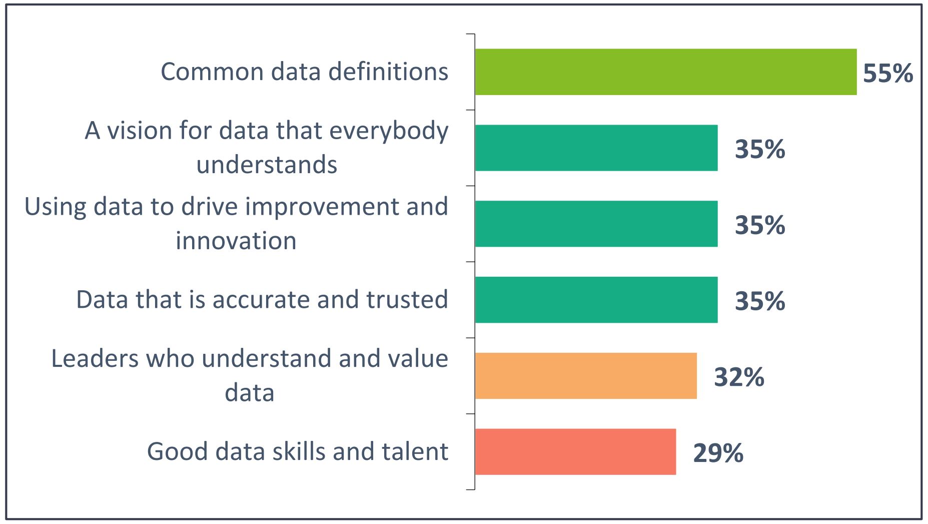
The second workshop was attended by 49 people, including representatives of local authorities, health, government and many more. It covered several areas, and used polls and breakout discussions too.

**On the right, clockwise from top left:** one of the polls' results; voting for priority areas for a strategy; contributors' ideas for areas a strategy should consider.

Contributors were asked: "*How much of a priority do you think it is to develop a data strategy for social care in Wales? (Scored from 1-5, 5 being the highest).*

**98%** of participants **voted** either **4** (29%) or **5** (69%).

Asked to choose their top 3 areas for a data strategy to involve, participants voted as per the box on the right:




Not just specialist skills, but basic skills are key so all can benefit from this shift

Stronger focus on Efficient systems - less time on gathering data, more time on analysing and linking to outcomes, improvement, making a difference

enabling communication to improve collaboration and shared learning

Leaders need to understand the data strategy and why it's important

Public engagement and ability to engage public on the issue of data and the use of their data is key

More focus on Collect once, use many times

How to get equal footing as Health: How do we drive collaboration with health from this strategy

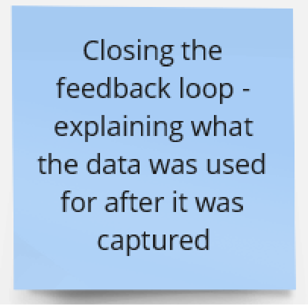
Almost too many guiding principles - Hard to remember what is covered and what is not

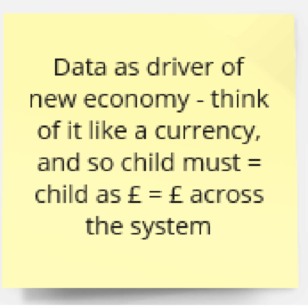
It's important that 'data always means the same thing' . 'Data Quality isn't explicit enough'

Individual/ experience data needs to be collected and used to inform

Data insights need to be fed back to the people supplying the information- mutually beneficial

clarity around what the scope of the data is? make sure we don't run before we walk


Closing the feedback loop - explaining what the data was used for after it was captured

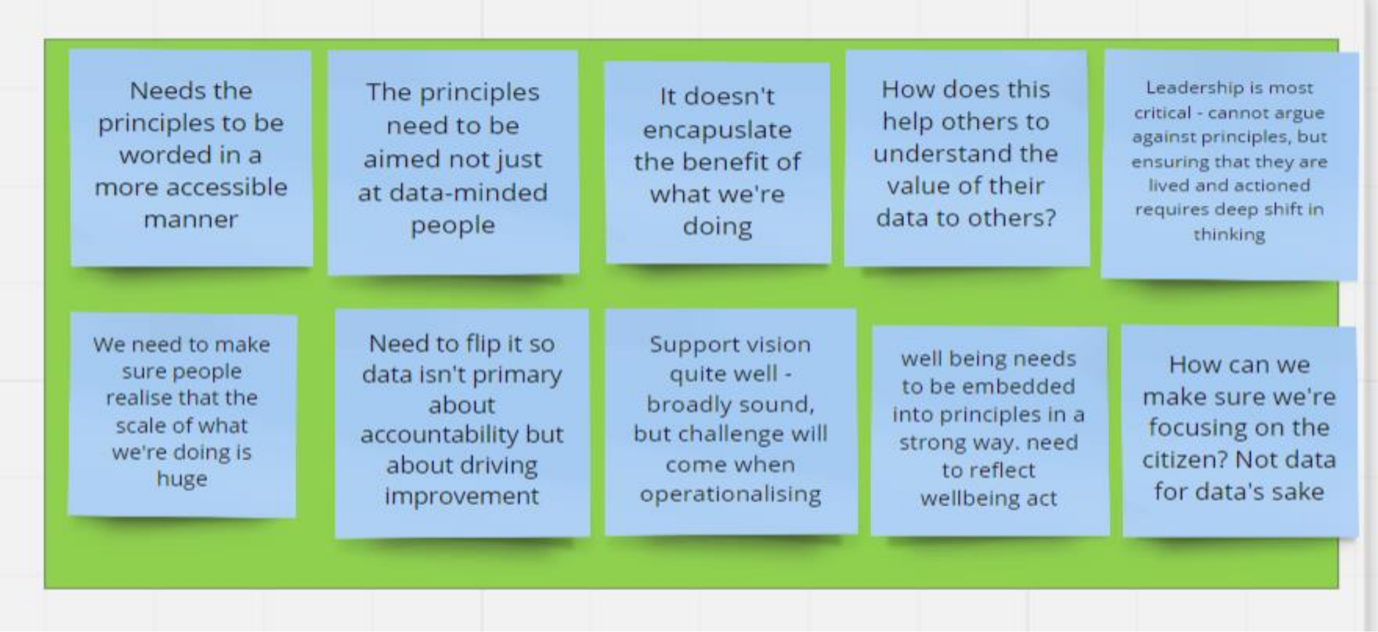

Data as driver of new economy - think of it like a currency, and so child must = child as £ = £ across the system

# Workshops (cont.)

**The second workshop also allowed participants to indicate the most critical components of the full data strategy, and to offer advice to leaders on how a data strategy could be delivered successfully.**

The workshops were well received by participants, with a number of people commenting that they'd like to be involved in future conversations about developing a strategy proper. This supports the findings of the stakeholder conversations, which were similarly positive and committed to supporting change.

**On the right, from top:** some of the feedback on the guiding principles; comments provided in response to questions about where the strategy should concentrate, and what advice should be given to leaders about implementing a strategy.



Needs the principles to be worded in a more accessible manner

The principles need to be aimed not just at data-minded people

It doesn't encapuslate the benefit of what we're doing

How does this help others to understand the value of their data to others?

Leadership is most critical - cannot argue against principles, but ensuring that they are lived and actioned requires deep shift in thinking

We need to make sure people realise that the scale of what we're doing is huge

Need to flip it so data isn't primary about accountability but about driving improvement

Support vision quite well - broadly sound, but challenge will come when operationalising

well being needs to be embedded into principles in a strong way. need to reflect wellbeing act

How can we make sure we're focusing on the citizen? Not data for data's sake

Strong, robust data definintions to ensure trusted data people can have confidence in and can be widely used

Data quality is vital - poor quality datasets are next to useless, so need definitions of what they're meant to be

Information Gov as an enabler, not a barrier

Leadership and senior buy-in feels critical to achieving much

Don't underestimate the voice of the citizen, people want to be informed

Be brave Be Bold

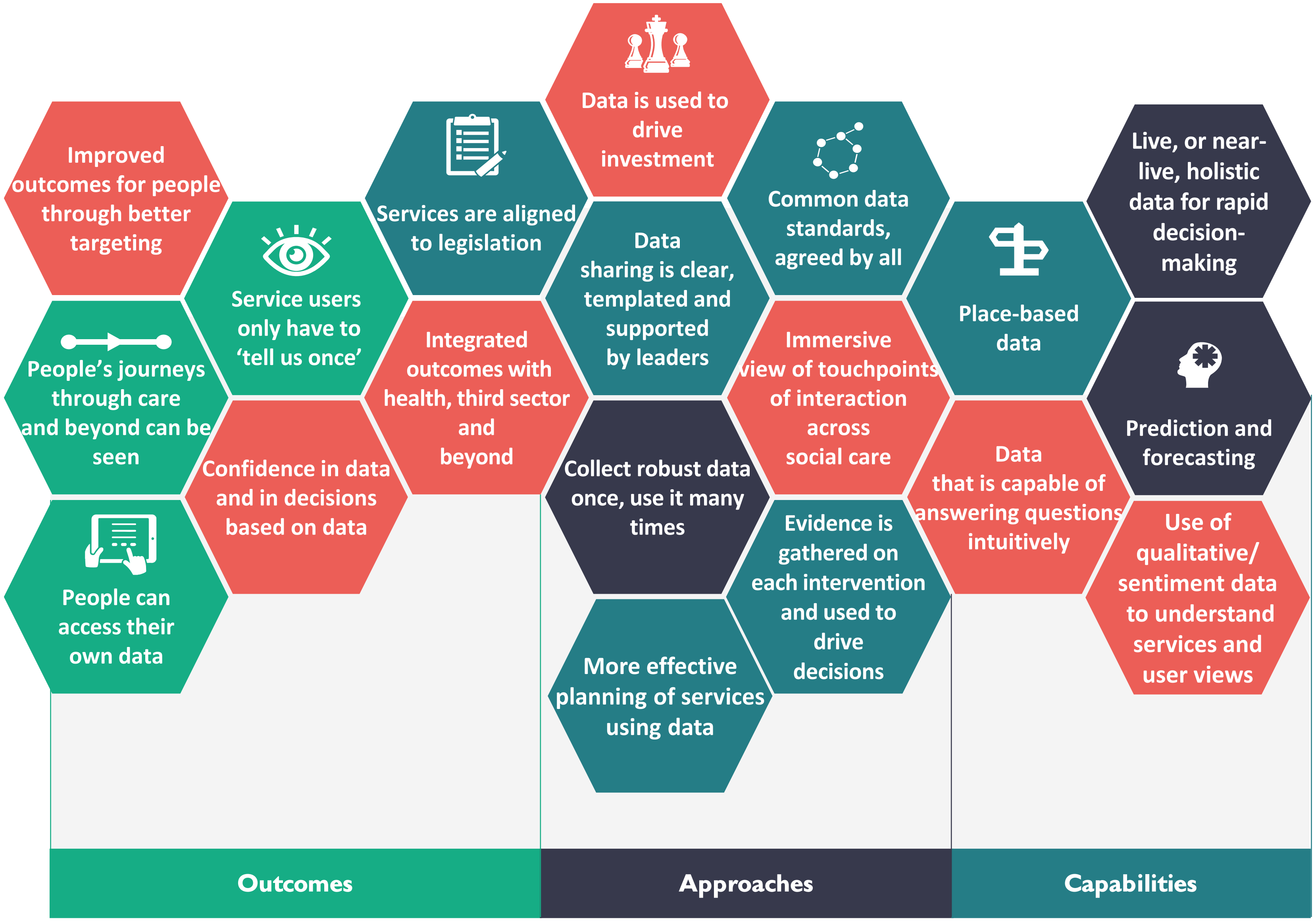
We must commit resources to make the ambitions realisable

Quick wins - skills and IT. Broader upskilling and getting the basics right

# Common ambitions for social care data

**In our conversations with stakeholders, a number of aspirations were discussed.**

On the right, we have set out the primary areas where ambitions were identified. Broadly, we have grouped these into three categories: **Outcomes**, i.e. the experiences of people and workers; **Approaches**, i.e. how ways of working will look different; and **Capabilities**, which covers new technology and skills that can help.



Improved outcomes for people through better targeting

People's journeys through care and beyond can be seen

People can access their own data

Service users only have to 'tell us once'

Confidence in data and in decisions based on data

Services are aligned to legislation

Integrated outcomes with health, third sector and beyond

Data is used to drive investment

Data sharing is clear, templated and supported by leaders

Collect robust data once, use it many times

More effective planning of services using data

Common data standards, agreed by all

Immersive view of touchpoints of interaction across social care

Evidence is gathered on each intervention and used to drive decisions

Place-based data

Data that is capable of answering questions intuitively

Live, or near-live, holistic data for rapid decision-making

Prediction and forecasting

Use of qualitative/ sentiment data to understand services and user views

**Outcomes**

**Approaches**

**Capabilities**

# Challenges for a data strategy in Wales

## People, Culture and Collaboration

- There is limited collaboration on data between social care and partners, or between services and citizens (such as self-service).
- There is a reluctance to share data even within organisations, let alone with other bodies or sectors, due to fears around information governance and the time commitments required.
- The importance of data is not always understood, and funding for data has been reduced over the last decade.
- There is little use of pilots, trials and research to gather the robust evidence that would indicate what works.

## Leadership and Governance

- There is no clear national lead for social care data, and national direction is felt to be unclear or missing.
- Leaders do not always understand data and push for it to be improved and promoted.
- Local authorities are only funded year-to-year, so long-term planning and investment is difficult.
- Data demands from central government are sometimes perceived as onerous and providers of data are not always clear what data is to be used for.

## Technology

- WCCIS is being used by a majority of local authorities, but not by all, despite ambitions for it to be a national system.
- Social care workflows and pathways are highly complex, limiting the number of systems suppliers.
- At present, there is no national data warehouse for social care, despite steps forward by NDR and the SAIL Databank (see **What assets and opportunities are there?** on page 19).
- Most organisations still work with basic or legacy tools to manipulate data, resulting in significant manual effort.

## Data

- The quality and accuracy of data is widely considered to be highly variable, as is access to it.
- The PIF has common data definitions, but these were not heavily publicised when it was launched on 1st April due to Covid-19.
- Not enough is done with qualitative data, and it is not used to its full potential in understanding and improving services.
- Much data is held in the third sector, but very little of it is used for planning services or assessing quality.
- Practitioners don’t always trust that the data they enter is used.

# What assets and opportunities are there?

Stakeholders across the system identified a number of existing strengths and areas of good practice that can support improvement.

### People, Culture and Collaboration

- Wales is a close-knit community where people are accustomed to working together. Due to its size, pooled budgets and resources should work more effectively.
- People with experience of social care services are enthusiastic to participate in improvement, with 'Measuring the Mountain' highlighted as an example.
- The Wales Centre for Public Policy is part of the UK What Works Network, providing research focus to the system.
- A number of data-focused organisations already exist in Wales, such as Data Cymru, and could be champions.
- Research bodies such as SAIL (see *Technology*) can help to share data, with 550 agreements already in place.

### Leadership and Governance

- Legislation is widely considered to lay a strong foundation for improvement of social services. The Well-being of Future Generations Act is regarded, including by citizens, as the standard to enable more integration across public services.
- Regional Partnership Boards (RPBs) and Public Service Boards (PSBs) help to broker interactions between public services, supporting social care voices to be heard and to plan more broadly. RPBs also have some research funding.
- Consultation is felt to be improving, such as in respect of the Performance and Improvement Framework.
- Recent decisions, such as in respect of homeless people during COVID-19, show a different way of working.

### Technology

- The National Data Resource (NDR), has its own e-research platform (as part of Swansea University's UK Secure e-Research Platform (UKSeRP) and is working in partnership with SAIL on health and care data projects. The NDR also supports the use of data for operational improvement.
- Advancing technology capabilities mean that, with the right data flows, standards and controls in place, the lack of a single social care system can be overcome.
- A Digital Health and Care Record is now being explored by the NDR programme, supporting seamless sharing.
- The SAIL Databank at Swansea University provides research and innovation for the Welsh public sector.

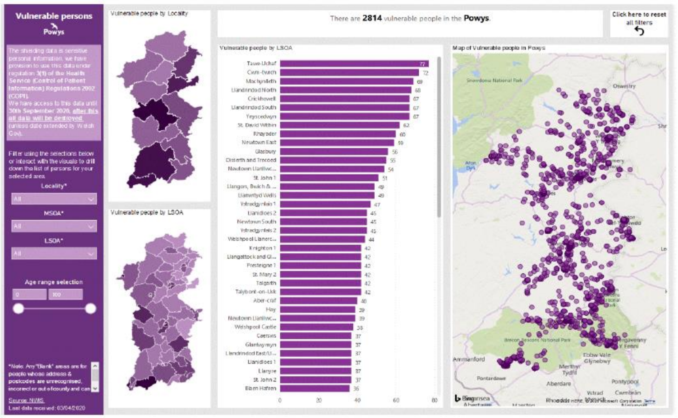
### Data

- Third sector organisations hold huge quantities of data, and are keen to work with the public sector on data-enabled commissioning and linking to public data.
- There are pockets of advanced data use in some local authorities (please see **Case study** on page 20).
- Health data is already held in quantity by the NDR and the SAIL Databank, providing an opportunity for linking to social care data for new and powerful insights.
- There are ongoing initiatives to bring together data about social care, including the NDR and WCCIS.
- Local authorities hold huge amounts of qualitative information that could be unlocked with the right tools.

**A set of case studies are provided *overleaf*,** demonstrating the effectiveness of some existing partnerships and activities.

**Case Study:** A data-enabled approach supports the response to COVID-19

**Powys County Council**


The shielding data is sensitive personal information, we have provision to use this data under regulation 3(1) of the Health Service (Control of Patient Information) Regulations 2002 (COPI).
We have access to this data until 30th September 2020, after this all data will be destroyed (unless date extended by Welsh Gov).

Filter using the selections below or interact with the visuals to drill down the list of persons for your selected area.

There are **2814** vulnerable people in the **Powys**.

*Note: Any "Blank" areas are for people whose address & postcodes are unrecognised, incorrect or out of county and can

Source: NWIS

Last data received: 03/04/2020

## Case studies

The case studies set out on this and the following pages are intended to demonstrate specific instances, projects or partnerships where best practice was demonstrated in line with the opportunities set out on the previous page.

Huge thanks to everyone who contributed to this series of case studies.

# Case study 1: using data for COVID-19 shielding

The COVID-19 crisis has been a significant challenge for councils. It has been essential for vulnerable and shielded residents to be quickly identified and supported. Powys County Council faced a particular challenge due to the county's relatively rural population distribution, in which many residents are already living in semi-isolated conditions. This made it harder to provide rapid and appropriate care.

Powys ICT and Business Intelligence and Analytics Team developed a Power BI dashboard to automate and streamline the identification of vulnerable people in Powys. Using the tool, which could be accessed online, the authority's Customer Service staff could quickly and easily access contact details of those in need.

The findings:

- The dashboard collated information from authority records, health board records and information from neighbouring authorities to provide a comprehensive picture of those in need and compiled an accurate list of their contact details to support customer service workers.
- The system enabled service workers to track their contact with individuals and automatically trigger further assistance and/or support from third party providers if required, improving service user experience and getting quick support for the most vulnerable.

This combination of data sharing, automation and an intuitive user experience was enabled by the long-term development of the Powys team, which had "literally no data" a few years ago, but has now grown into an advanced function and partnered extensively with other councils.

## Lessons for social care

Tailored risk management trialled during COVID-19 has many applications to social care. To achieve these outcomes, the council has had to invest in its data team and in market-leading tools such as Power BI.

**Case Study:** The combining of data about health, maternity and care proceedings could help to prevent babies entering care in the future

**Swansea University, Cafcass Cymru and SAIL Databank**

# Case study 2: linking data to prevent care admissions

A 2020 research paper, authored by Dr. Lucy J. Griffiths of Swansea University and others, aimed to consider the rapid rise in the number of babies taken into care in recent years.

The report, *One thousand mothers in care proceedings in Wales*, was the first of its kind to link family court records to maternal health data in Wales, painting a picture of the health needs of both mothers and babies who come into care proceedings. In doing so, it helps us to better understand the kind of intensive early intervention that might be needed.

The findings highlighted the vulnerabilities of women whose babies are subject to care proceedings in the first year of life, including the very high proportion with significant prior mental health conditions at or before attending antenatal care.

In particular:

- Over half of the pregnant mothers in this study reported an existing mental health condition at their initial antenatal assessment;
- Three-quarters experienced a mental health-related GP or hospital appointment
- Pregnant women who go on to have babies removed are not normally unknown to maternity services, and their babies are not significantly less healthy than those whose mothers are not subject to care proceedings.

The study used anonymised administrative data from Cafcass Cymru combined with maternity and other health data using the highly secure systems for linkage and anonymisation established by the SAIL Databank.

The findings support the Welsh government’s current policy of investing in mental health perinatal services, and help public sector organisations to prevent future admissions to care.

**Lessons for social care**

This study demonstrates the value of sharing data from different services – in this case, to inform the future planning and design of support for families and children, as well as mental health services.

**Case Study:** Collecting and publishing data on care home vacancies could support better care planning

**Welsh Government and Data Cymru**

# Case study 3: tracking and publishing availability of care home places

Prior to the COVID-19 outbreak, Welsh Government officials explored the potential for an online tool to display consistent, up to date information on the capacity of regulated services across Wales, including current vacancies, in one place. Data Cymru had been tasked with building on the existing Dewis Cymru website which provides information, advice and assistance to the public. The tool developed was known as the care and support capacity tool.

In March 2020 Welsh Government made a decision to escalate development in response to COVID-19.  Data Cymru were subsequently able to roll out a limited version of the capacity tool, focused on adult care home vacancies, with an accompanying data dashboard made available to local authority and health board commissioners.

Data Cymru engaged extensively with care homes to encourage uptake of the tool. As of September 2020, 896 care homes across Wales have signed up to use the tool, representing around 85% of adult care homes in Wales.  Additional dashboards have been developed for Health Board discharge teams, and to track the tool's rate of takeup by local authority area.

Data Cymru has received positive feedback on the tool from care home providers, although challenges remain in reducing duplicate information requests in some areas. Developments planned for this project include a public-facing website to display high level vacancy information, enabling members of the public to understand what provision in their local area when considering care homes for themselves or loved ones. The potential to expand the tool to other regulated services, including domiciliary support services, is also being considered.

**Lessons for social care**

A single, national system to monitor care home vacancies has many potential beneficiaries including Welsh Government, Local Authorities and Health Boards. However, the tool is ultimately reliant on individual providers regularly submitting their data, therefore their continued support will be crucial in further developments.

**Case Study:** The impact of home repairs on physical and mental health

**Carmarthenshire County Council, Swansea University, NHS Wales Informatics Service, and SAIL Databank**

# Case study 4: researching the impact of home repairs

Carmarthenshire County Council (CCC), working with Swansea University, wanted to know the answer to a research question: does improving housing benefit the physical and mental health of residents?

Between 2007 and 2015, CCC invested £138m in improving 8,558 homes. This included replacement bathroom and kitchen units, upgraded heating and electrics, insulation, double glazing of windows and doors, new fencing and more.

The proportion of residents aged 60+ who have emergency admissions to hospital for selected conditions (cardiovascular, respiratory, and fall and burn injuries) was monitored to see if it was affected by the improvements provided.

To achieve this, CCC worked with the SAIL Databank and NHS Wales Informatics Service to replace address information with an unidentifiable code, ensuring that links to people’s health information were safely anonymised.

The findings:

- Upgraded electrical systems resulted in a reduction in emergency admissions of almost 40%
- Double glazing of windows and doors reduced admissions by around 30%
- Wall insulation and work on garden paths also resulted in significant reductions.

The results of the study allow for housing repairs and upgrade activity to be concentrated in areas which have the greatest impact on the health of residents, supporting all public sector partners’ ambitions to help people to remain resilient, and in their own homes, for longer.

**Lessons for social care**

Understanding the impact of home repairs on health outcomes helped CCC to target investment. Knowing more about social care through better data could equip other local authorities with the evidence to plan services and support with the most positive impact.

# Delivering a data strategy in Wales

# Guidance offered by contributors

**The text below summarises some key advice for the data strategy from our contributors and stakeholders.**

The strategy needs to provide a realistic and achievable roadmap for local authorities, reflecting our resourcing constraints and capabilities.

There needs to be adequate training and investment in developing data practices. We'd require more formal information sharing pathways across authorities, third party and outsourced providers, and national bodies. We'd like to see the insights produced from the data we share and use them to improve our services.

Our technical infrastructure must also be able to support our data ambitions, and we need help to target investment in our data tools in order to bring about innovative change.

The data strategy must focus on the integration of social care data with health and other services' data, including third sector, as well as improving the quality of social care.

Ultimately the vision is to have one standardised, cleansed and safely accessible dataset for all of Wales.

The strategy must be aligned with and support our legislation, as well as the vision set out in 'A Healthier Wales'.

It must outline how investment in data will enable the achievement of goals and provide measures to evaluate impact.

Leaders need to understand the data strategy and why it's important.

The strategy must outline how data and information will flow across the social care ecosystem, and it must set out how we will begin to use standardised data quality standards and data definitions.

It also must highlight how information is to be shared across organisations, including the third sector, to ensure we can create and maintain a single holistic picture of care in Wales.

# Considerations for developing the strategy

**A National Data Strategy for Social Care in Wales would include a number of themes.** Contributors to our second workshop were asked for their views, which are summarised below under a set of conceptual themes.

**Use cases**

A use case approach will be at the heart of the data strategy, and will focus effort and investment where participants in the system themselves see the greatest potential. In this way, use cases enable change that is culture- and people-led, not technology-led.

For more details on use cases, **please see pages 30-32.**

## Key themes for a data strategy

**Leadership, direction and ownership:** Contributors felt it was critical for leaders to drive the data agenda and to provide clarity, purpose and accountability. Leaders should not only support their data functions, but be data champions themselves as well.

**Data standardisation:** This was perhaps the most common theme picked out by participants. Without confidence in the quality and meaning of data, few people felt that progress would be made.

**Using pilots and proofs of concept:** Participants noted that there are many existing initiatives to connect up as part of a strategy, and urged the strategy to "walk before it runs" by showing quick wins early on. Links to existing data, like population, could also help.

**Collaboration:** Alignment on both priorities and ways of working was considered essential to foster integration and avoid silos, in relation to both practice and data. A "data broker" role could help to break down barriers, and allow the data sharing that is greatly needed.

**Skills, talent and capacity:** It was felt to be important that, since gathering good data takes time, people should understand why it matters – whether they turn it into reporting or input it in the first place. Resourcing was also considered an essential issue to address.

**Qualitative data:** Contributors were interested in the way that qualitative data such as feedback and reviews could change services, ideally in an integrated way with more 'traditional' data. People often connected these with outcomes.

# Data-driven investment and commissioning

**A national data strategy for Wales will enable social care delivery organisations, and their many partners, to provide more effective, evidence-based services to those most in need.**

### Better, integrated outcomes

A data strategy will set out how social care data can be linked to health, housing, voluntary sector data and more, creating one seamless service user journey and enabling organisations across the system to tailor their care to the whole person.

### A focus on prevention

Among many benefits of more powerful and effective uses of analytics and data science, local and national organisations will be able to identify trends and patterns, and to gather and use evidence to provide support to people and families before issues escalate, unlocking both human and economic benefits.

### Personalised, co-designed care

Data is a core enabler of accessibility for service users to view and interact with their care records and plans, putting the individual and their needs at the centre of their care. People have the right to expect data about them to be held safely, used thoughtfully, and updated regularly.

### Consistent data, trusted decisions

An essential component of a data strategy is a robust project plan for social care data to be managed, stored and governed consistently across Wales. Standardised, comparable, high-quality data will support decision-making at all levels and will contribute to the development of an evidence base for ever-stronger decision support. Data will be seen as an asset and a resource by all organisations supporting social care in Wales.

### A data-enabled workforce

The strategy will include a focus on skills and talent, both for data professionals and for frontline workers, leaders and managers. It will explore resourcing and investment, and consider solutions such as pooling and the use of hackathons to bolster in-house skills.

### Using data to drive investment

With more powerful, reliable data, local and national organisations will be empowered to develop evidence-driven business cases to articulate their challenges and secure targeted investment.

### Stronger research capability

Datasets will be better integrated, managed and stored across Wales, enabling researchers, regulators and policymakers to see the ‘bigger picture’ and help them make informed recommendations on how to support and improve social care services.

### Defined ownership and accountability

A key output for a data strategy is a defined roadmap, informed by the findings of this discovery phase but developed much further, that sets out agreed actions in respect of each of the areas above. For each area, the strategy will recommend lead and supporting agencies, leveraging the specific strengths of each organisation in the wider system to contribute to the implementation of the data strategy. Finally, the strategy will also consider the leadership and direction required at a national level.

# Co-design and co-production

**The future data strategy must actively involve citizens and people who use care and support.**

In this scoping phase, the majority of contributors worked for formal organisations, whether public or third sector. Please see **Appendices** for more detail.

The strategy will learn from the experiences of groups who are seldom listened to, such as people who are BAME, LQBTQI+, or in custody.

To help, we propose to learn from experts such as the Co-production Network for Wales, whose five principles can act as a guide:

1. Build on everyone's strengths
2. Develop networks across silos
3. Focus on people's lives, not systems
4. Work on the basis of great relationships
5. Enable people to be change makers

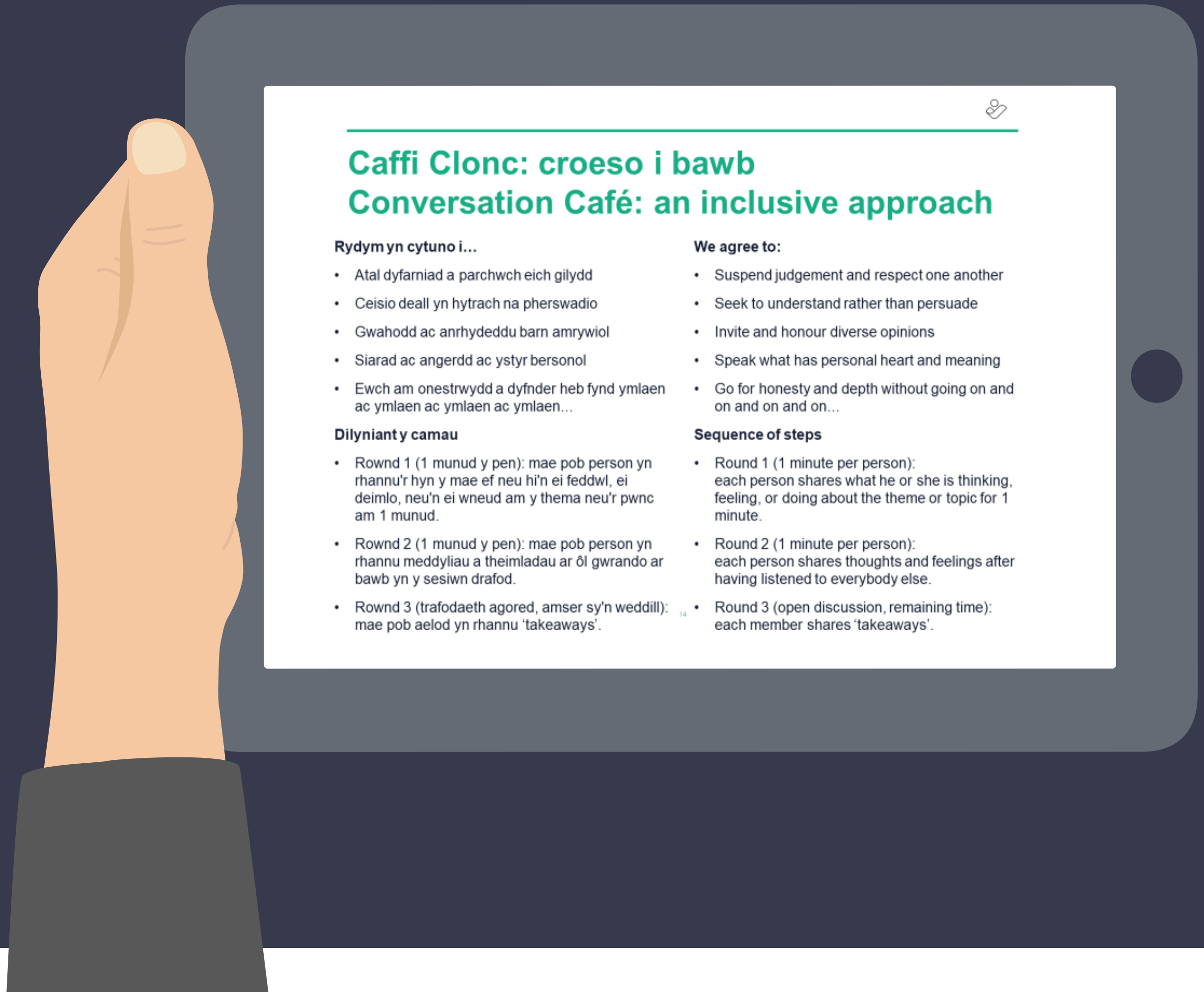
A number of methods could be used, such as grassroots events, community forums, and citizen journeys.

# Accessibility and communication

In the post COVID-19 world, it has never been more important to identify and offer accessible collaboration methods. With many social service users requiring shielding and only essential visits taking place, all public-facing organisations are working with citizens to set out safe approaches for the future.

Any strategy must also be available in plain language. Previous policy and legislation has benefited from significant work to develop accessibility to a wider audience, including easy read, children's and young people's summaries, and intuitive websites. The data strategy will consider all of these options.

Finally, under the terms of the Welsh Language (Wales) Act 1993, the Welsh Language (Wales) Measure 2011 and other policy and legislation such as the Welsh Language Standards Regulations (No. 1) 2015, the strategy must be fully available in Welsh. Even more importantly, people are entitled to access public services provided in the Welsh language. As such, there are a number of implications for the strategy to consider:



## Caffi Clonc: croeso i bawb
## Conversation Café: an inclusive approach

| **Rydym yn cytuno i...** | **We agree to:** |
|---|---|
| • Atal dyfarniad a parchwch eich gilydd | • Suspend judgement and respect one another |
| • Ceisio deall yn hytrach na pherswadio | • Seek to understand rather than persuade |
| • Gwahodd ac anrhydeddu barn amrywiol | • Invite and honour diverse opinions |
| • Siarad ac angerdd ac ystyr bersonol | • Speak what has personal heart and meaning |
| • Ewch am onestrwydd a dyfnder heb fynd ymlaen ac ymlaen ac ymlaen ac ymlaen... | • Go for honesty and depth without going on and on and on and on... |
| **Dilyniant y camau** | **Sequence of steps** |
| • Rownd 1 (1 munud y pen): mae pob person yn rhannu'r hyn y mae ef neu hi'n ei feddwl, ei deimlo, neu'n ei wneud am y thema neu'r pwnc am 1 munud. | • Round 1 (1 minute per person):<br>each person shares what he or she is thinking, feeling, or doing about the theme or topic for 1 minute. |
| • Rownd 2 (1 munud y pen): mae pob person yn rhannu meddyliau a theimladau ar ôl gwrando ar bawb yn y sesiwn drafod. | • Round 2 (1 minute per person):<br>each person shares thoughts and feelings after having listened to everybody else. |
| • Rownd 3 (trafodaeth agored, amser sy'n weddill): mae pob aelod yn rhannu 'takeaways'. | • Round 3 (open discussion, remaining time):<br>each member shares 'takeaways'. |

- **Simultaneous translation, which requires proactive recording of staff language skills**
- **New data requirements, such as care assessments offered in Welsh**
- **How to collect data on language skills, for which self-assessment is not fully sufficient**
- **Ownership and accountability for categorising and collecting language data**
- **Welsh language support for the strategy development itself**

# A use case approach

> **A targeted transformation in a business process to address a specific issue that has been identified by an organisation.**

**A data strategy for social care in Wales is proposed to focus on a use case approach. A definition of a use case is set out above.**

Use cases have a number of benefits. They:

- Introduce new and effective ways of working
- Ensure that the most impactful and achievable issues are tackled first
- Act as a ‘quick win’ to drive support for the data strategy
- Build confidence in organisational data transformation
- Give an indication of the future potential creative solutions at the disposal of the organisations covered by the strategy.

Use cases are best used as a method of planning manageable projects under an overall programme that can deliver tangible benefits quickly.

They are sometimes described as ‘spread betting’: not all ‘bets’ – each ‘bet’ being a use case – will necessarily pay off, but because all use case working groups will prioritise benefits realisation, use cases that do not deliver as expected can be halted.

**A process map showing how use cases are governed within a data strategy is set out overleaf.**

## Methodology

**01** Define the problem

**02** Who does the problem affect?

**03** What outcome needs to be achieved?

**04** How will the outcome be achieved?

**05** What will the impact be?

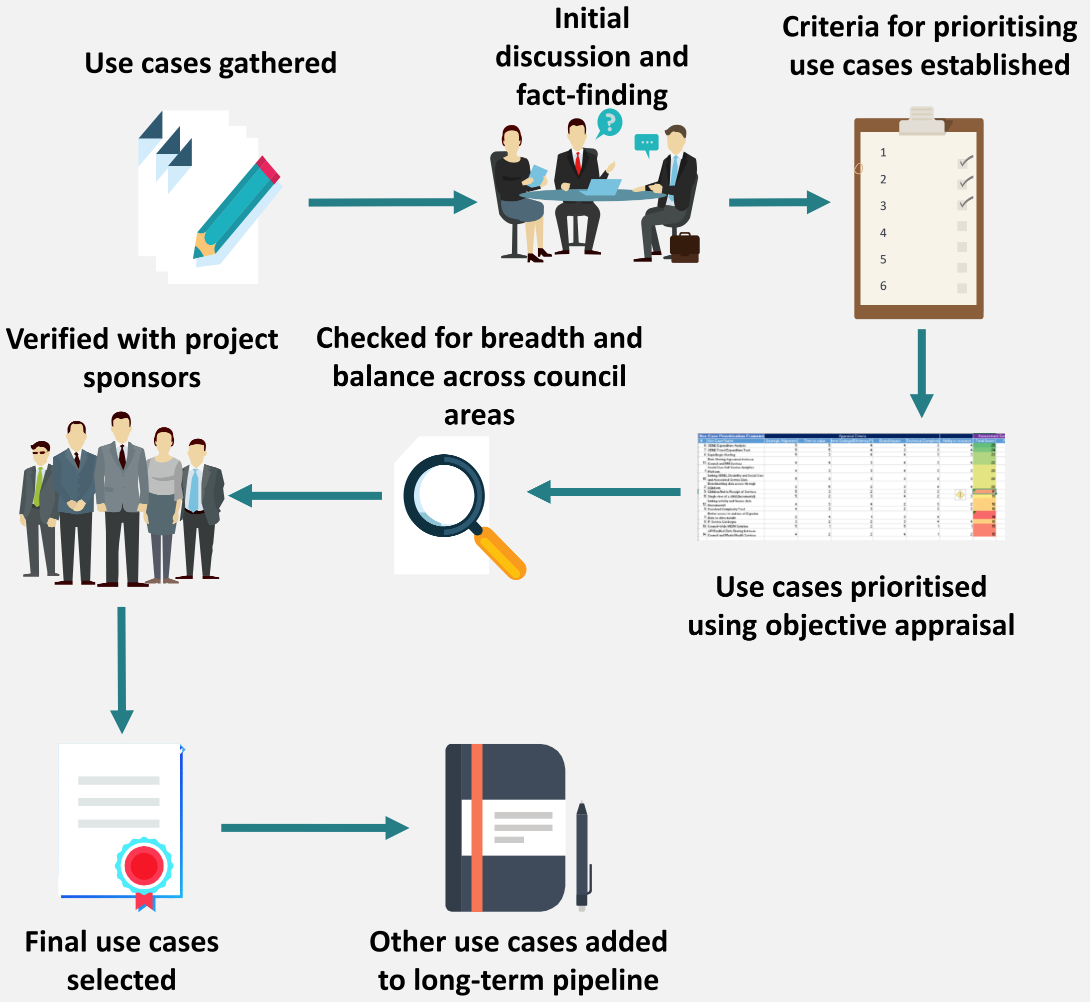
**06** How will we measure the impact?

# Use cases: process flow

**A data strategy would aim to initially develop a longlist of use cases, based primarily on stakeholder interviews and documentation review conducted in the course of the development process.** A set of agreed criteria are then used to develop a shortlist of prioritised use cases, as shown below, which is then subject to a verification process and approved for delivery.

## Appraisal criteria

- **Breadth of coverage:** How many services/people are impacted by this use case?
- **Impact on service users:** How much will service users benefit from this use case?
- **Impact on services:** Will this use case make services more effective or efficient?
- **Wider profile:** How will this use case impact partners or the public profile of social care?
- **Difficulty:** Do the tools and capabilities to deliver this use case already exist, and to what extent?



Use cases gathered

Initial discussion and fact-finding

Criteria for prioritising use cases established

Use cases prioritised using objective appraisal

Checked for breadth and balance across council areas

Verified with project sponsors

Final use cases selected

Other use cases added to long-term pipeline

# Example use case: Digital Health and Care Record

Digital technologies and online services have become part of our daily lives. Having good information which drives better decision making is key to delivering an excellent service to patients and improving their care.

**The digital health and care record (DHCR) will create a trusted and linked 'master' record for patients, a single source of the truth that can be used across care settings** to make relevant information available as needed while reducing duplication.

The process to build out the DHCR as a use case is shown below, according to the methodology set out ***on the previous pages.***

**Methodology**

**01** Define the problem

**02** Who does the problem affect?

**03** What outcome needs to be achieved?

**04** How will the outcome be achieved?

**05** What will the impact be?

**06** How will we measure the impact?

1. **Data cannot easily be shared between social care and health service**, meaning that patients are not always seen in the round, and inhibiting their ability to see and be involved in their care planning
2. **Users of social care and health services, their families – and services**, which may struggle with coordinating services, engaging citizens, and more
3. **A trusted and linked 'master' record**, a single source of truth
4. **A combination of initiatives and projects, supported by the National Data Resource programme**, which collectively provide the underlying national data architecture and infrastructure to facilitate the linkages that the DHCR requires
5. Users of care and support benefit from holistic, thoughtful planning and care that **helps them to stay safe, resilient and independent for longer**
6. **An evaluation plan will accompany the programme of work**, setting out metrics to be tracked and reported on to evidence impact. These metrics will consider enhancements that the DHCR will enable for programmes such as Digital Services for Patients and the Public and the Welsh Clinical Portal.

Enabled by…
**Powerful user stories**

**Empowered national leadership on data sharing**

**Cross-organisational oversight and collaboration**

**A project team with the experience and knowledge to drive it**

# A vision and guiding principles

# The “problem” statement

During the course of the discovery phase, we continually proposed, tested and rewrote a “problem statement” setting out why change is needed. This is intended to provide a very short, high-level summary of how things currently are.

A huge thank you to all of those in our community of participants who contributed to this statement.

> “Welsh Government has set out an aspiration for data to inform all decisions made in Wales.
>
> The potential value of data about social care is not fully recognised, and there are concerns about standardisation, data quality, and the clarity of purpose when data is collected. Data are not consistently used effectively in research and administration, and to tell stories about people’s journeys through social care. The many organisations that deliver, regulate and support social care do not always share data to check that services are working well.
>
> Ultimately, these challenges mean that it can be difficult to determine how effective social care services are, to predict and model future needs, and to make evidence-based decisions to improve these services for the people of Wales.”

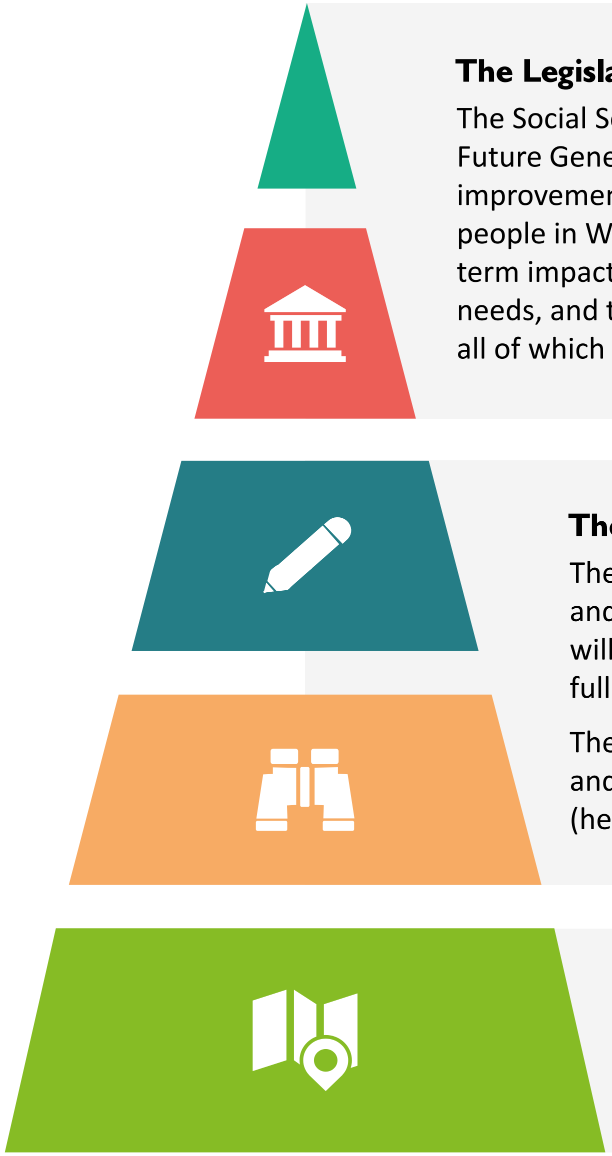
# Developing a vision

Any vision for social care data in Wales must align to the legislative framework set out in the Social Services and Well-being (Wales) Act 2014 and the Well-being of Future Generations (Wales) Act 2015, and should set out how data about social care will contribute to that framework.

The data vision and guiding principles were developed through the course of the discovery phase and were reviewed at the two workshops held with contributors (see right for more details).

**The Welsh Language**

Through the Well-being of Future Generations (Wales) Act, among other legislation, public bodies must work towards a thriving Welsh language. This involves, among other things, the collection of data about Welsh language skills and preferences relating to both professionals and citizens.



**The Legislative Framework**

The Social Services and Well-being (Wales) Act and the Well-being of Future Generations (Wales) Act set out a mandate for the improvement of social services and the health and well-being of people in Wales. These include the requirement to consider the long-term impact of decisions, the sharing of intelligence about unmet needs, and the wider promotion of integrating health and social care – all of which require data to be successful.

**The Data Vision**

The vision for data will draw from the legislative context and will outline how social care and social services in Wales will look when data about these services is being used to its full potential.

The vision was developed through the discovery interviews and was reviewed by participants at our first workshop (held in June 2020).

**The Guiding Principles**

The guiding principles outline the common ways of working required to deliver the data vision. They were reviewed in detail by participants at our second workshop (held in July 2020).

# The vision: what could social care data enable?

The proposed data vision for social care in Wales, set out here, consists of four broad ambitions. These support the key legislative drivers, concentrating on the sharing and accessibility of data, the use of data as evidence to improve outcomes, and the involvement of people experiencing social care in helping to make decisions about their own services.

**An increasingly holistic view of a person across all relevant services, combining data safely to allow people’s needs and strengths to be fully understood**

**Decisions made about social care services build on evidence and research, from within the sector and beyond**

**There is an ever-growing evidence base helping to identify what works, and every new pilot has an evaluation plan**

**Citizens can see themselves holistically, providing informed consent to share their data with other services that can help them**

# The guiding principles

***Interoperability**
Interoperable systems are able to talk to each other to share data – a critical component of the change we need.

**The proposed guiding principles, below, act as ways of working that enable the vision. These have been reviewed in depth by breakout sessions at our second workshop.**

- People who use services are empowered to understand, access, contribute to and use data held about them, working with the services they receive to improve their own outcomes

- Empowered, visible, expert data leadership exists at both national and local levels, promoting the use of insight in policymaking and helping to develop communities of data practice

- Clear, unified data standards and definitions are in place across Wales to ensure that social care data is timely, high quality, comparable, trusted and facilitates improvement nationwide, with data curated and catalogued in a consistent way

- Social care services share data, both internally and with public and third sector partners, and work with other organisations to develop expertise and experience in sharing data safely and lawfully

- Social care data, and the wider services they support, are seen as equal partners with health and as part of a collective health and social care agenda for Wales, as defined in legislation

- All organisations commit to evaluation plans whenever they change existing services or pilot new services, contributing their learning to a national knowledge base, including through the use of open data

- Technical solutions are procured to a common set of data standards, are fit for purpose for their intended use, are **interoperable***, and are collectively procured where appropriate

- Organisations at all levels invest in data skills and talent in line with the ambitions set out here and in the data strategy, working to a robust business case basis, and focusing on insight and universal data literacy to enable improvement

- Research, regulatory and delivery partners work together to provide expertise, data and oversight, helping to compensate for funding limitations within public services, and ensuring that data providers see the fruits of their labours

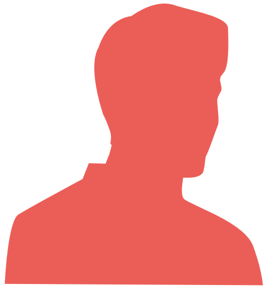
- Where new or changed data is required from service user-facing organisations, an agreed process of consultation and change management is used; data is curated as an asset, allowing investment and use to be targeted

# What will the change feel like?

**Citizen or person who uses care and support**
I feel like my voice is finally being heard. I am able to co-produce my care plan based on my needs, and the data recorded about me supports that. Any new person working with me can use these data to get an overview of who I am as a person, not just my needs, and so I don't have to tell my story all over again.

When I start supporting someone new, I now have access to a more detailed care history, which helps me build our relationship. I can also use the more intuitive interface to work together with the person I support, so we can work together on their long-term outcomes.

**Practitioner**

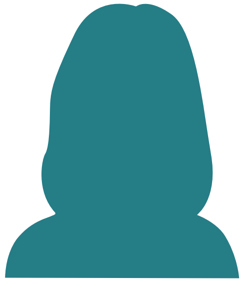


I feel confident in the data I can access, and it looks right – it corresponds to the strengths and challenges we face. I can more easily use these insights to plan and budget effectively, and I now know where I need to invest to achieve the greatest improvement.

**Director of Social Services**

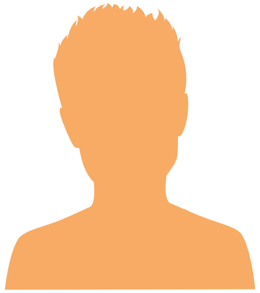
I have access to better data analysis tools which means I can automate more mundane tasks. I now spend more time providing deeper insight on trends and exceptions, developing and using evidence, and using data to support business cases for change.

**Data Analyst**



It is much easier for me to understand the quality of social care in Wales, because I can trust the data available to me and I know that it's comparable between places. This allows me to focus on supporting innovation and improvement, such as by developing and sharing best practice.

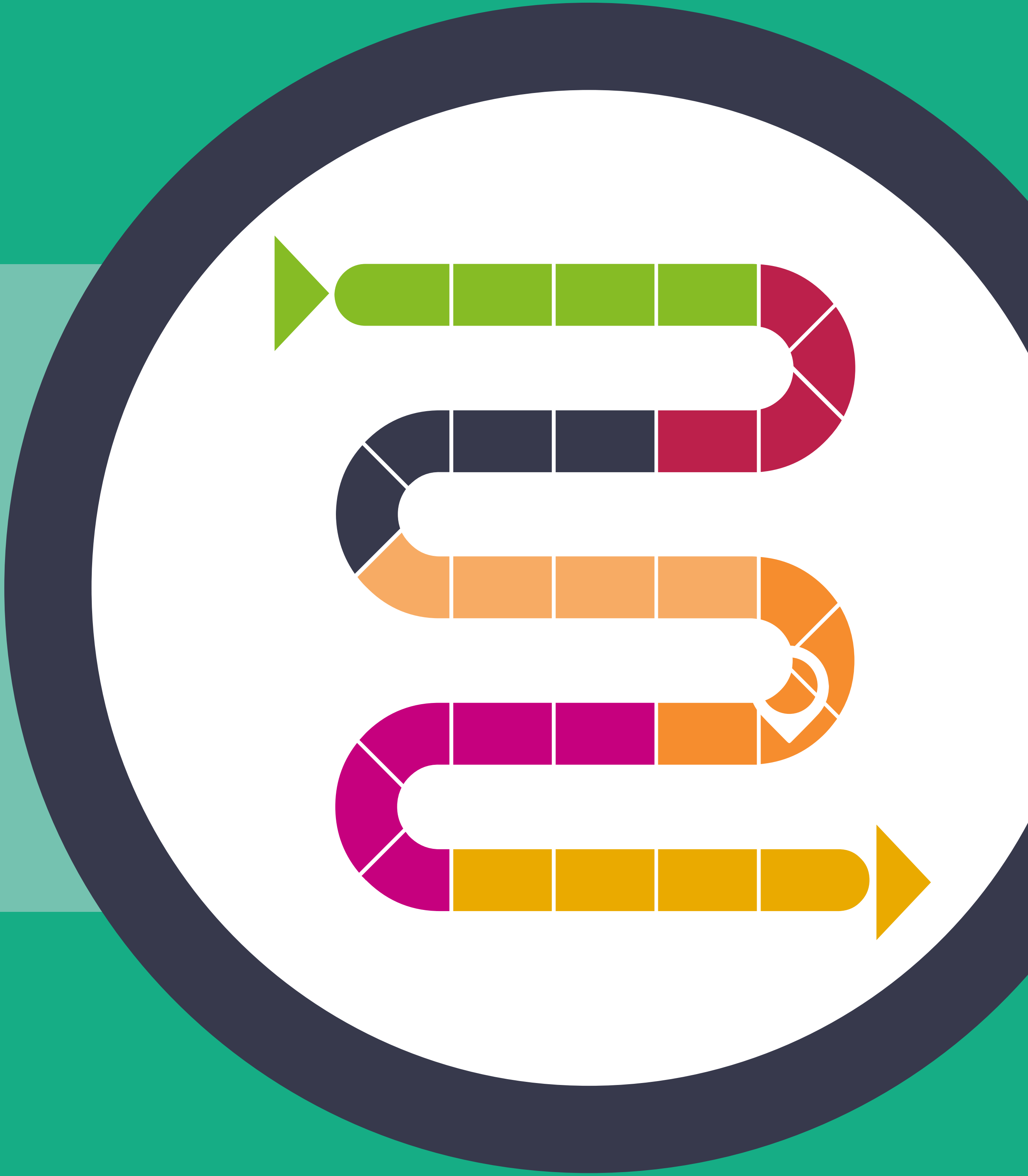
**Regulator**



There is a named lead organisation for social care data in Wales, which acts as a broker, expert and champion. I can now model and predict future trends and use this to help the sector plan and deliver seamless, place-based care that is digitally-enabled and responsive to people's needs.

**Policymaker**

# Proposed next steps



# Proposed next steps

We propose that, to continue the development of a national data strategy for social care, that three components, or strands, are pursued as set out below.

### Strand 1: A Statement of Strategic Intent

We propose that Welsh Government and Social Care Wales, supported by NHS Wales Informatics Service, develop and issue a statement of strategic intent.

This statement will set out the ambition and requirement for all relevant organisations to work together as required to develop a data strategy roadmap (see below).

### Strand 2: A Data Strategy Roadmap

A roadmap-based data strategy will be agile and modular, and will be based on the development of use cases. Within the overall context of the statement of strategic intent, the roadmap will set out a programme of separate workstreams, delivering benefits in series – a development of the approach outlined below.

### Strand 3: Quick Wins

Quick wins are a form of use case that can be progressed quickly. Quick wins could be new, or could consist of new investment or focus for previous initiatives.

This discovery report provides a wealth of evidence about the change that is required. We propose that working groups are identified and pilot projects begin at pace to test approaches and unlock tangible benefits as soon as possible.

# What happens if we don’t act?

**To continue as is without proceeding with the suggested activities would be likely to perpetuate the current challenges outlined in this report (*see page 18*). Looking ahead, the key risks for the future could be as follows.**

| | |
|---|---|
| **Continued limitations to the use of social care data** | **Contributors to this report have outlined that they find social care data hard to find and use, and that they often do not trust it even when they have access to it.** Continuing as is would mean that social care data is always seen as remote and unreliable, and consequently its use will be limited. |
| **Threat to effective integration of health and social care** | **Social care data is challenging to connect to health data due to data quality and information governance challenges.** While health data is far from perfect, it benefits from well-known standards and definitions, widespread use in research, and more streamlined central direction and governance. If social care data is unable to close at least part of this gap, using them together for integrated care will be hard. |
| **Potential lack of compliance with Social Services and Well-being Act** | **The Performance and Improvement Framework set out in the Code of practice in relation to the performance and improvement of social services in Wales, issued under section 145 of the Act, means local authorities will face new requirements for the use of evidence in decision-making.** At present, evidence-gathering, use of research data, and measuring experience are all areas where capabilities are generally limited, and each would be targeted as a workstream by a data strategy. |
| **Loss of belief and momentum** | **Contributors to this report have participated in 1:1 or group interviews, up to two workshops, and have often provided written suggestions or answers and provided supplementary material.** There is huge enthusiasm for a data strategy to provide a clear forward direction on data about social care in Wales (**see pages 12-17**, in particular). Not to proceed now could persuade many stakeholders that change is impossible, or is not a priority for Wales. Furthermore, the energy and momentum that the COVID-19 crisis has generated around the better use of data would be lost. |

# Strand 1: Statement of strategic intent

# Strand 1: A Statement of Strategic Intent

## A statement of strategic intent, or SSI, will guide the future data strategy.

Welsh Government, working in particular with Social Care Wales and supported by other organisations such as NHS Wales Informatics Service, will be responsible for the development of the SSI and will seek to achieve ministerial endorsement in order to formalise the role of the statement and of the future data strategy as a clear, demonstrable component of the place of data within the wider social care and health system.

We would propose that the SSI takes as a starting point the vision verified through the discovery phase set out in this this report (**see page 36**), and amends it at the discretion of the process set out above.

The National Data Resource (NDR) programme may offer a useful exemplar, since it too was prepared based on a Ministerial statement of intent that then guided its development. This statement was based on four pillars, as is also the case for the vision set out in this report.

As part of the SSI and to support the development of the other strands set out **in the following pages**, this report recommends that Welsh Government formally identify a lead organisation for social care data that is empowered to act on behalf of the wider system, once partners across social care (and other relevant areas, such as health, housing and the voluntary sector) are able to endorse common approaches through the further strands to be set out.

Linked to the above, there must be recourse to this lead organisation where blockers are identified to work undertaken under the overall strategy and to deliver the SSI, requiring this organisation to be able to take a national leadership role in order to supplement its role of engaging, communicating and seeking common purpose.

The role of citizens and people who use care and support in developing the SSI should be carefully considered in line with the commitments to co-design and co-production elsewhere set out in this report (**see page 28**).

# Strand 2: Roadmap to a data strategy

# Strand 2: A Data Strategy Roadmap

**A Data Strategy Roadmap will set out the main programme of work to be undertaken to develop and implement components of the data strategy.** The below outlines the key workstreams we would anticipate being involved in a roadmap.

### Define governance

It is our assumption that, by the time that a roadmap is defined, leadership of the data strategy programme will have already been set through the statement of strategic intent (**see page 43**). It will remain to set operational governance for the work.

### Define funding and resourcing

In connection with the governance stage above, and learning from the experience of delivering quick wins, an approach to funding and resourcing the data strategy programme will be agreed.

### Incorporate quick wins

Learning from the previous quick win phase will be distilled to inform future planning.

### Evaluation plan started

The project will begin a parallel workstream to plan and define impact of change, focusing on people who use care and support.

### Agree use case workstreams

Workstreams to be undertaken through the roadmap will be developed through consultation, events and further 1:1 conversations. Potential opportunities and challenges faced by each workstream will be explored in detail, with the aim of profiling a suggested set of initial tasks.

### Identifying ownership

A key element in the workstream development process will be exploring, defining and agreeing ownership. This will be consultative and collaborative, but will provide clarity.

### Implementation planning

The workstream development process will be subject to an approval checkpoint before leading into implementation planning, which will align the required tasks to capacity and organisation focus in order to land effectively.

### Assembling working groups

Utilising the relationships built during the project (some, ideally, dating from the scoping phase), working groups will be assembled to support lead individuals and agencies to deliver the implementation.

# Strand 3: Quick wins

# Strand 3: Quick Wins

**The journey to data maturity and effectiveness is an incremental one, and is enabled by some core capabilities that cannot easily be built without a strategy to develop our data, people and culture.**

However, some obvious ‘quick wins’ do exist. These are use cases which can begin and progress more rapidly, and tend to conform to the themes identified below.

**Building an evidence base**

It’s easy to start gathering evidence – every new or changed service could have an evaluation plan, and commissioning could require the same

**Learning from ourselves**

Powys County Council, for example, has prototype definitions for 92 of 97 Performance and Improvement Framework indicators

**Technology may not be a barrier**

Whether different organisations use different systems may not matter, if their data can flow to a common place - so standards matter most

**Data is not just performance**

Data can be used to monitor and evaluate, but also to plan and deliver better services – culturally, it should be seen as a resource

**Qualitative data is hugely important**

New techniques can allow us to learn much more from qualitative data such as case notes. Technologies like Natural Language Processing (NLP) use free text to help provide a better view of services

# Strand 3: Quick Wins

**To retain focus and momentum, a set of quick wins will be begun early, potentially in parallel to the statement of strategic intent**. Some potential quick wins, tied to the themes set out **on the previous page**, are set out below.

These quick wins are use cases, as set out **on pages 30-32**. They are use cases that can proceed more rapidly, typically because more has been learned about them in the course of the discovery phase. Use cases, the quick wins included, are a learning process, and at this stage the below suggestions still warrant further enquiry to assess feasibility as we prepare to launch them.

**In order to progress at this pace, however, there should be agreement between partners on funding, resourcing and strategic recourse in the event of barriers and challenges.**

Form a working group to develop the data standards consulted on and set out in respect of the Performance and Improvement Framework (PIF), including by exploring further development of activity definitions as well as understanding the user experience and considering the use of research evidence. This group will leverage the existing consultation undertaken and relationships formed through the development of the standards.

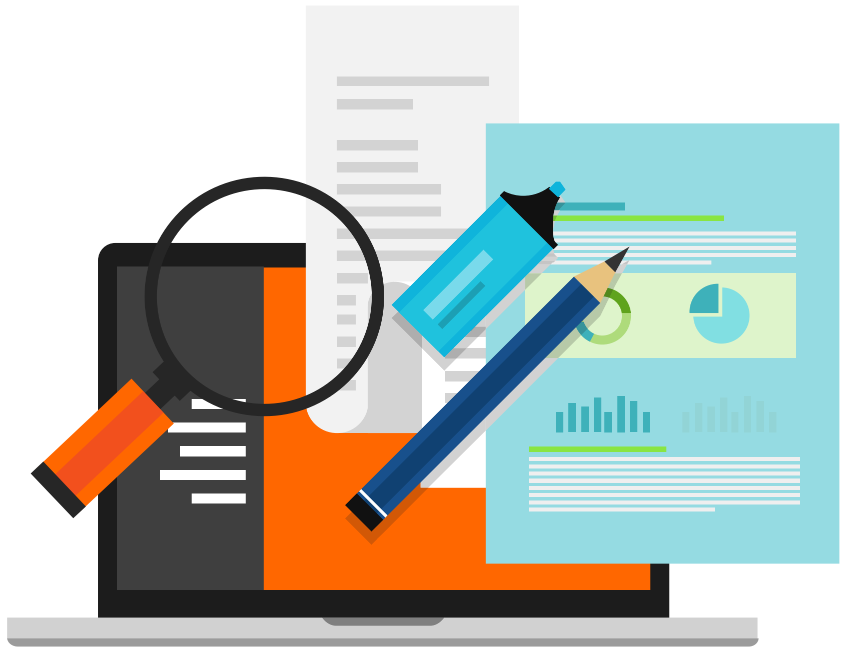
Identify a pilot local authority to work with the SAIL Databank, specifically to test the development of exemplar data sharing processes and documentation for other councils to use, as well as setting out use cases for research applications to inform the ongoing roadmap and unlock defined, tangible benefits for local authorities.

Commission a survey of attitudes, among citizens and people who use care and support, towards data sharing – potentially linked to a preliminary group of use cases in order to include a sense of potential purposes.

Begin to develop, with the support of a joint grouping between social care, the academic sector and preferably one or more of the What Works centres, a simple best practice guide to accumulating evidence for later decision-making which will support the forthcoming duty on local authorities in respect of evidence-based service design.

Commission an independent review of all social care data-related duties on local government, identifying processing required and uses arising from data presently collected, the burden of data provision, and the alignment between the two. This review should also consider where information could be released as open, public data.

# Appendices



# Appendix 1: Stakeholders interviewed

**A huge thank you to all of the people who contributed to this strategy**. The people named below were interviewed during the course of the scoping project, and many also participated in one or more of the workshops we held.

| Name | Organisation |
|---|---|
| **Kate Young** | All Wales Forum |
| **Susan Cooper** | Bridgend County Borough Council |
| **Dave Street** | Caerphilly County Borough Council |
| **Bryn Harries** | Cardiff & Vale University Health Board |
| **John Peters** | Cardiff & Vale University Health Board |
| **Margaret Rooney** | Care Inspectorate Wales |
| **Martyn Palfreman** | Carmarthenshire County Council |
| **Martin Elliot** | CASCADE, at Cardiff University |
| **Beth Flowers** | Children's Commissioner for Wales |
| **Karen Benjamin** | Children's Commissioning Consortium Cymru (4C’s) |
| **Mike Jones** | City and County of Swansea Council |
| **Suzanne Draper** | Data Cymru |
| **Phil Diamond** | Gwent Regional Partnership Board / Blaenau Gwent County Borough Council |
| **Clem Price** | Health Education and Improvement Wales |
| **Ryan Cunningham** | Health Education and Improvement Wales |
| **Heidi Morris** | NHS Wales |
| **Helen Thomas** | NHS Wales |
| **Kathy Mason** | NHS Wales |
| **Paul Howells** | NHS Wales |
| **Heléna Herklots** | Older People's Commissioner for Wales |

# Appendix 1: Stakeholders interviewed (cont.)

| Name | Organisation |
|---|---|
| **Emma Palmer** | Powys County Council |
| **Alisha Davies** | Public Health Wales |
| **Nathan Lester** | Public Health Wales |
| **Kevin Pett** | Regional Board Wales West |
| **Trevor Palmer** | ResponsABLE Assistance, and experience of social care |
| **Ashley Akbari** | SAIL |
| **David Ford** | SAIL |
| **Gwyndaf Parry** | Social Care Wales |
| **Lisa Trigg** | Social Care Wales |
| **Sue Evans** | Social Care Wales |
| **Damian Bridgeman** | Social Care Wales Board Member, and experience of social care |
| **Leigh Davies** | Torfaen County Borough Council |
| **Martin Gibson** | Welsh Audit Office |
| **Becky Cox** | Welsh Government |
| **Bethan Sherwood** | Welsh Government |
| **Claire Thomas** | Welsh Government |
| **Fliss Bennee** | Welsh Government |
| **Glyn Jones** | Welsh Government |
| **Owen Davies** | Welsh Government |
| **Rachel Jones** | Welsh Government |
| **Aled Roberts** | Welsh Language Commissioner |
| **Lowri Williams** | Welsh Language Commissioner |

# Appendix 2: Documentation reviewed

**A range of policies, project documents, pieces of legislation and more were reviewed in the course of developing this report**. The documents named below were specifically examined, but many more were consulted briefly or partially.

| Name | Name |
|---|---|
| Digital Health & Care Strategy for Wales (2015) | Records Management Code of Practice for Health and Social Care 2016 (2016, applicable to the NHS in England; reviewed for context) |
| Social Care Research and Development Strategy for Wales 2018-23 (2018) | The national outcomes framework for people who need care and carers who support them (2019) |
| Welsh Government Performance and Improvement Framework (first phase, 2020) | The Economic Value of the Adult Social Care sector, UK final report (2018) |
| NDR Programme Business Case Justification + Appendix | WCCIS history overview (informal) |
| Outcome Measurement in Wales Implementation Subgroup (minutes, February 2020) | 1000 Lives Improvement (ongoing) |
| WCCCIS governance structure (informal) | Gwent Regional Partnership Board Area Plan 2018/19 |
| WCCIS Information Management Board Terms of Reference (2020) | Prosperity for all National Strategy |
| WCCIS Governance Model (2019) | Parliamentary Review of Health and Social Care in Wales |
| Implementation of the Regulation and Inspection of Social Care (Wales) Act 2016 (letter sent by Welsh Language Commissioner) | Measuring the Mountain: What Really Matters in Social Care to Individuals in Wales (final report, 2019) |
| Code of practice in relation to measuring social services performance (consultation document – summary of responses, 2020) | A shared data approach more accurately represents the rates and patterns of violence with injury assaults (2017) |
| Social Services and Well Being (Wales) Act 2014 | Maximising the Use of Routine Data for Research in Wales (2013) |
| A Healthier Wales – our plan for health and social care (2018) | Meetings that matter: talking together proactively to support learning, development and research mindedness (2019) |
| [Various more informal sources, such as the Chief Statistician’s blog] | |

Social Care Wales, South
Gate House, Wood Street,
Cardiff, CF10 1EW

info@socialcare.wales

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Social Care **Wales**