Scottish Care
Voice of the independent care sector

'SEEING THE DIAMOND IN SOCIAL CARE DATA'

A HUMAN RIGHTS-BASED PERSPECTIVE ON CREATING VALUE IN SOCIAL CARE DATA

JUNE 2021

Introduction

In terms of social care, Scotland is data rich, but intelligence poor. There are many different data storing systems which make the space fragmented, complex and difficult to navigate. It is often the case for those who access care and support, that everyone you interact with such as a social worker or care worker, uses a different system to capture and store your data, and that data is not or cannot be shared across systems.

Social Care is an intervention grounded in human rights and therefore the way that we collect, hold and use data in the sector should also align to this paradigm. Given the multiple interactions people may experience in relation to accessing support, people should only have to tell their story once. One of the challenges we hear most often from people accessing care and support is having to tell their story and provide information repeatedly, which is emotionally and physically exhausting. It can mean that people often begin to miss out the most challenging and therefore most pertinent parts when it comes to finding the right intervention, the more they are forced to repeat themselves.

In addition, drivers such as duty of care, regulation, funding and resource, and pandemic response expose a real need to explore this work as a matter of urgency. However, this should not detract from individual data collected from personal devices and an individual's choice or desire to incorporate that into wider health and social care datasets to potentially inform prevention and early intervention. The concept of technology in care should not be unusual – as citizens, many of us use it in our everyday lives. This familiarisation should prevent unnecessary barriers to adopting technology in care.

Fundamentally, social care as a sector, are experts in keeping the person at the heart of care and involved in decisions. This needs to be recognised and supported by those working with social care to augment the experience. It is through partnership working that transformation will be made in people's lives with investment in the appropriate technology that will make a difference. To do this, we need to shift the focus from operational measurements, to be able to understand how technology and data create value in enhancing experience.

In this paper we share our vision for social care data and share the findings of a series of data forums hosted by Scottish Care involving colleagues from across the social care sector, industry, academia, and government. We articulate the value and potential of social care data and the need to create the right conditions to ensure that its worth can be uncovered and harnessed. We aim to reveal the diamond in data towards a person-led vision which creates value for all.

The Why?

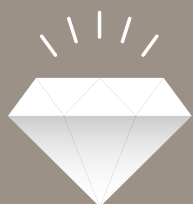People should only need to tell their story once

To meet the fundamental purpose of social care

Scotland is data rich but intelligence poor

Fragmented data collection, standards and access
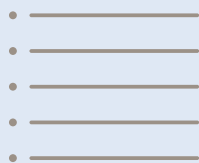
Duplication and waste

Potential

The How?

Involve multiple perspectives

Develop a set of Principles

Create a Vision

Map other systems and data collections

Collaborate

Co-design product

Test, learn, share & embed

Vision

- Citizen-controlled
- Rights-based
- Person-led
- Meeting the needs, wishes and aspirations of people, not satisfying requirements of the system

Our vision for social care data in Scotland is to start from a human rights perspective that enables the person to have control over their data and how it is shared to initiate care and support on their own terms. We aspire to a destination where data collected is person-led not system satisfying; is based on the needs, wishes and aspirations of people for their care and support; informs the design of services and planning, and the resulting indicators of performance and success.

Data Forums

In Autumn 2020, Scottish Care hosted a series of three Data Forums. The purpose of these were to bring together people across social care who have an interest in the potential of data, but with a specific aim to explore a proof of concept around citizen owned data. Discussion was wide ranging covering challenges, ethics and recommendations to be explored. Much of the content of this paper is influenced by those sessions, including the co-production of a set of principles for social care data.
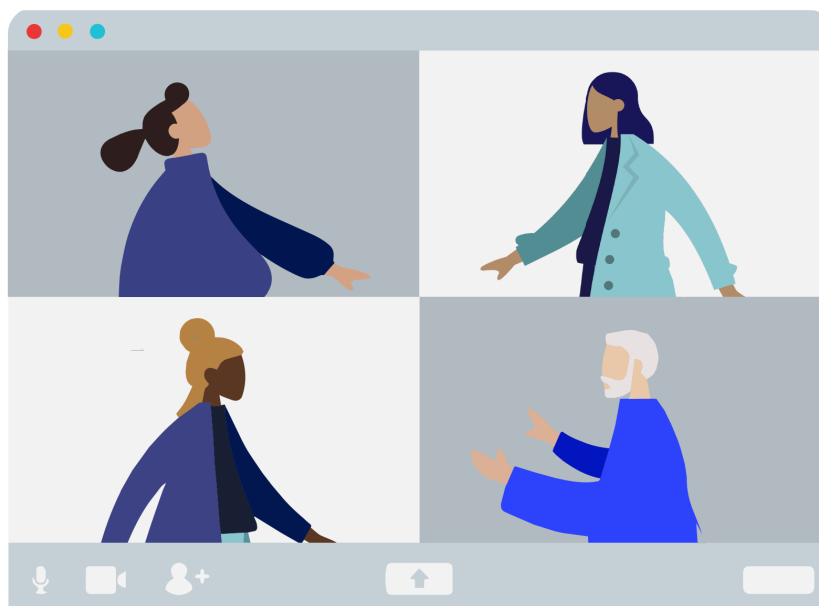
Ethics and the value of a rights-based approach to collecting, analysing and applying data

Social Care is an intervention grounded in human rights and therefore the way that we collect, hold and use data in the sector should align with this paradigm. In addition, one of the key strengths of the social care sector in Scotland is the diversity of care providers offering a range of services and supports. However, a key challenge for providers is being able to share and harness data with other services and providers to enhance ways of working and the care experience. Although there are many incredibly useful and life-changing software programmes available, and this should not be underestimated, across the many agencies and systems operating in social care, we cannot currently accumulate and analyse in a reliable and ethical way. This means that we cannot articulate or even envision the value of the data that we hold. Therefore data is held which is simply not used, but full of potential.

It is important to find a balance in data sharing based on what is valued and consented to by individuals, what is valuable and has potential for wider society and what is valuable in terms of reducing the burden of effort on staff. Data should be shared with consent and choice which means a person should not have their data shared or used simply because they access care and support, nor should that be brought into other fundamental information.

Critically we need to reconcile that we currently collect and apply data to suit the needs of services, regulators and wider aspects of the system. If we apply a rights-based approach to the way that data is collected, analysed and applied, then we need to reframe this perspective to facilitate a citizen-led approach. Data would become the commodity of and under the ownership of the individual, collected and applied to meet their needs, wishes and aspirations for support.

Overcoming power and historic culture challenges

Historically, the value of social care has been overlooked thus creating an invisible barrier to investment across the sector, not only in relation to technology and digital. Where movement has been made to optimise social care data, the purpose has been to support the NHS, rather than the focus being on those accessing care and support or the wider integration across health and social care. As an example, what is measured and described as 'delayed discharge' refers to circumstances when a person is unable to access the right support in the right place at the right time for a variety of reasons which need to be explored and managed, yet the concept is colloquially and inappropriately reduced to the term 'bed blocking'.

In such a scenario, people who access care and support are an invisible population because only part of their data and story is known to different people in the system. This highlights a risk of intervention becoming health-led and reduced to an exercise in data mining. Measurement and performance in this context are therefore driven by the expectations and resulting requirements of the system, rather than the expectations and outcomes of the person and support required.

Instead, the system should be driven by the needs of the person and those who interact with it such as frontline care staff. In addition, for this multi-sector system to work, there must be trust in the data provided by those from other disciplines and with different skillsets, as well as including self-entry from citizens. For example, an assessment must be transferable and have co-created value for each perspective involved.

Applying a co-design approach to developing a new methodology for data will ensure that what is developed is not only fit for purpose but will also foster that trust.

De-mystify data and data-sharing

A current challenge is how the system can make it easier for the person to understand their data, how it is held and used across health and social care. Data sharing should be a reassuring experience for people accessing care and support, with simple and effective ways to make sure it is shareable and creates value in their care experience. For genuine involvement, those who access care and support need to understand how they have control and ownership of their data and what that means for them.

There needs to be a shift in language, to speak plainly about data and there is a responsibility to explain data fully and clearly. Parts of the system should be challenged to think through who they are sharing data with and why, adopting a purpose and value-led approach that is grounded in human rights, rather than a traditional 'share everything' approach. Across the forums we heard of how everyLIFE are creating a data protection and security toolkit to support staff. In addition, NHS digital are recasting all their information governance guidance to make it easier for frontline teams to know what can and should be shared. This could equally be a helpful resource to inform data in social care.

Public and sectoral buy-in to data sharing would need to be achieved. Forum members proposed a groundswell campaign to highlight the benefits of data sharing. To support this, Scottish Care designed a template for sharing across networks to create a campaign to demystify data - #datachangeslives (Figure 1).
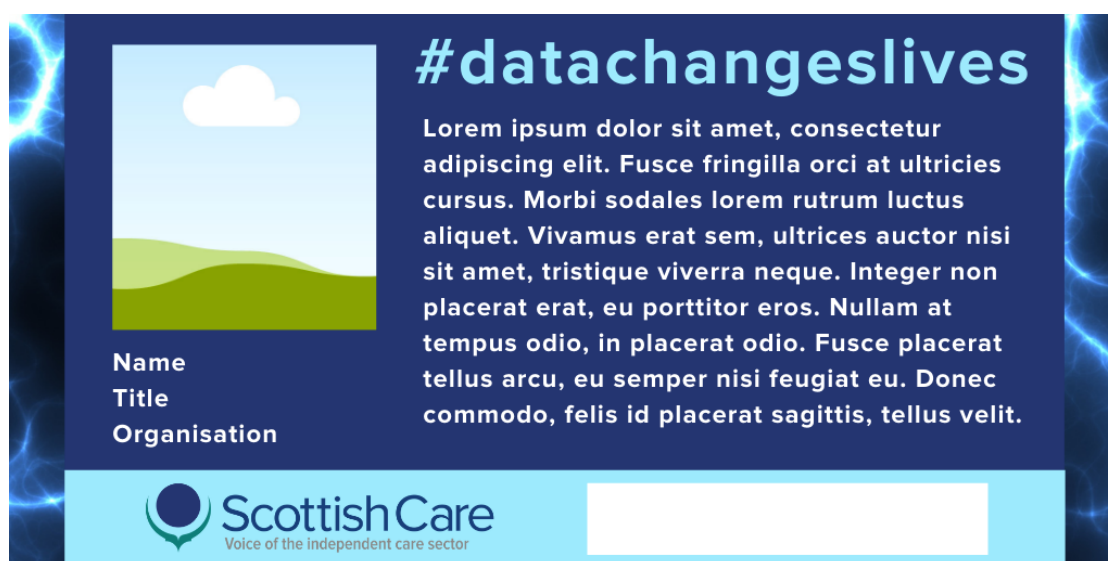
Figure 1. Example of the #datachangeslives social media campaign template

Understanding the purpose and value of data in social care

Data can be used to improve lives if it can work across different systems, but this purpose must always be defined, understood and implemented within a context of human rights. There needs to be a shared understanding of what we mean when we refer to data and when we refer to information. In addition, there are often technical and semantic issues about interoperability. However, the issue around interoperability is well defined with the need to translate between different systems and to be able to rely upon the trustworthiness of the data.

Work should be done to establish who should be involved in defining the purpose of data collection and sharing including those who access care and support. For social care providers, this could mean having access to relevant data and being able to make data-led decisions within an ethical framework underpinned by key outcomes to ensure data informs, e.g., quality and positive aging.

To date, there have been local initiatives around data, looking at social care data collected within social services. However, there needs to be further work on how to bring that data together and to make it accessible to those accessing and involved in providing care and support to allow greater understanding of transitions and people's individual care journeys, including how their needs may change over time. There are some Local Authorities working collaboratively with providers to understand the care they are commissioning, using data to inform quality and develop a more preventative approach.

Given the complexity of the data across health and social care, it is important to also understand the wider data landscape in terms of systems and data collection. However, the landscape very quickly becomes overly vast and given the pace of development in this space and continual change this is a challenging task. Kumu has made an attempt and further work in this space would offer greater insight into the value and potential of[1] social care data.

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[1] https://kumu.io/ruchirshah/data-infrastructure-for-scotland

Removing 'Friction, Effort, Risk and Cost' - a single source of clinical truth and a single source of personal truth.

To gain traction and relevance, Mydex have suggested that work must look to removing 'Friction, Effort, Risk and Cost' towards a single source of clinical truth and a single source of personal truth. There must be the semantic interoperability to translate from one environment to another, but also carry the trust so each party can be confident in decision-making.[2] Discussions around the concept of 'citizen-owned data' and 'citizen-controlled data' highlight the differences in system accountability and centralisation. Using the term citizen-controlled data offers greater certainty around choice and presents benefits to all in terms of enabling the flow of data from many sources within ethical parameters. It is recognised that the term 'ownership' can present as uncomfortable given the legal implications which may cause concern to those working in the context of health and social care and could prevent cultural buy in.

Portability is also fundamental as well as a 'cleansing' of duplicated data with data being required in different formats by different organisations. Solutions which seek to streamline data sharing and reduce duplication will be important, e.g., tools such as the 'Safety Huddle' hosted on TURAS which was created by and for the benefit of the system as a measurement tool during pandemic response in 2020, but could with investment prove to have value for people accessing health and social care.
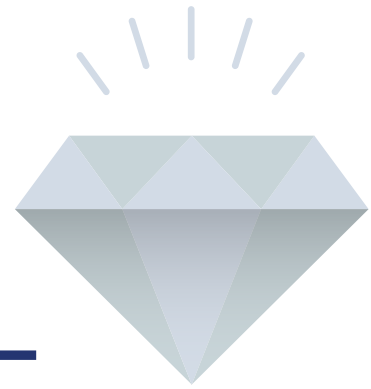

[2] https://joinup.ec.europa.eu/collection/nifo-national-interoperability-framework-observatory/3-interoperability-layers

Pressure points become areas of potential

The real step change which can be made with social care data is to acknowledge the whole system and individual choice. It is the current pressure points which would benefit most from a more effective approach to data collection, sharing and analysis. Points of transition are often highlighted as areas in need of improvement such as hospital discharge to a care setting. These types of transition involve a raft of paperwork travelling with or following the person upon discharge. A digital discharge pathway co-created with all stakeholders would be truly transformational and the assets created would be equally as applicable and valued across all care settings. In addition, people who access care and support in their own homes often have multiple interactions with different professionals which is another area which would benefit from investment and test of change in relation to data sharing.

The concept of a minimum data set
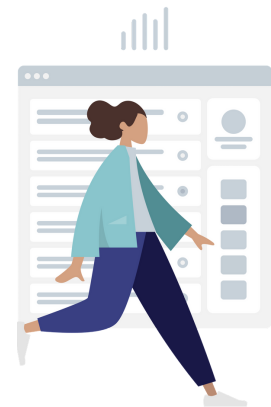
The methodology and reason for data collection varies by organisation and the professionals involved e.g. care at home assessment does not mirror social work assessment and data required by regulators is different from data required by local authorities. Consideration of a core minimum data set has potential to eradicate multiple assessments and duplication of formats of data required. Form participants discussed that on the face of it, a 'top 10' valuable data items for particular care and support groups could be incredibly useful, but there is difficulty in finding agreement on what those should be, and danger in limiting the data collected. Principles and professional judgements are hard to capture, and it would be impossible to determine in a finite sense which data different parties need. Conversely however, the single approach would offer consistency across health and social care for the 'clinical source of truth' as well as confidence that the data has been gathered, generated, inspected, and verified in a reliable way. Insights from the Care Home Innovation Partnership discovered 15 core items of data collected by care homes which could be used to create the foundation for a minimum data set for care homes.

[3] https://www.medrxiv.org/content/10.1101/2020.08.17.20176503v2.full-text

In addition, there is inter-disciplinary research underway being led by 'DACHA' in England which may offer solutions and further insight.[4] There is currently a huge amount of data which the system requires even if no one can determine why. In addition, a minimum data set does not allow for granularity where it is needed. Fundamentally, data sets must have purpose and when they are reduced, often that purpose is lost. It is here that the minimum data sets risk a trade-off between information and quality in relation to care. Yet when we apply the rights-based approach, this can be mitigated if we start from the position of what a person needs and what those who provide care and support need to understand the components of that. We must continue to question 'who are we creating value for?' and 'how do we unleash the potential of social care data?'.

Social Care workforce

Just as there is a risk that those who access care and support are lost amidst their data, there is also a risk that data and measurement become a predominant focus over the skills and expertise of those who work in social care. An example of this lies in the implementation of electronic call monitoring whereby staff clock in and out of visits to a person's home and are measured against this. This process has led to contractual arrangements between providers and purchasing authorities which do not allow for unforeseen circumstances to arise nor consider staff travel time between visits to people's homes. We are aware of a tragic example of a lack of understanding and empathy about social care commissioning experienced by a care worker who was supporting a spouse while waiting for an ambulance to arrive on the death of their partner. On calling the commissioning authority to alert them, instead of condolence and support they were informed that they would not get paid for the additional time. It is vital that we do not devalue and deskill our workforce by reducing their role to time and task. It is the relational aspect of social care that makes it so effective. Instead, their skills and expertise should be valued and recognised, and any work on data to support the workforce should be co-produced with them. In parallel, expectations and vision would need to respect the capacity and competence of the care sector. To explore future potential, Scottish Care previously collaborated with the Innovation School at The Glasgow School of Art on the future of care at home.[5] The outcomes of this work led to the creation of speculative future workforce roles, two of which involve interactions with data and technology to improve care and support. This work also informs conversations around cross-sectoral skillset and training. In addition, the context of implementation is important as it will fail if not applied in a realistic and achievable way. For example, it may be that upskilling is required of the social care workforce. If this is the case, this should be as seamless as possible, and staff should have adequate support and resource to engage.

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4 https://arc-eoe.nihr.ac.uk/research-implementation/research-themes/ageing-and-multi-morbidity/amm01-developing-resources-and

5 https://futurehealthandwellbeing.org/future-of-care-at-home

Resource, finance and market limitations

In Scotland, social care is mostly funded by the public purse. Currently, contractual arrangements do not offer costs for innovation and investing in technology and digital that could result in transformation for people accessing support and the social care workforce. The resource limitations create a real lack of inherent investment in the sector to support any work despite a desire to do so.

Financial and resource investment in social care data will be required to establish and implement news way of working. Not only to establish systems, but to upskill those using them. However, the reduced duplication and preventative approach which better use of data can afford makes this an invest-to-save process.

In addition, current data systems were created in a competitive market where the data itself holds value. Updating and amending those systems will cost money to developers, but also for those who currently use them. If we continue current procurement-based exercises, there risks market domination by a small number of large developers with a wide offer, rather than a dynamic market where innovation thrives.

Leadership, policy and the role of Government in enabling change

COVID response has stalled work on social care data by Scottish Government. However, the need for a national approach to what we value in terms of data and evidence is recognised, as well as more complex items such as capturing outcomes to allow data to augment wellbeing and the experience of care and support.

Data collection at both local and national level could allow for analysis which would showcase effectiveness of services, but also expose what is required to support system continuity. This could also serve as a way to measure government responsibility to meet social care objectives of supporting people who access care and support to live best life possible in their own circumstances.

To date, IT changes have come out of necessity and continue to be driven by the needs of the wider system. For example, the current situation in pandemic response has driven the need for data such as the creation of the safety huddle tool.

Moving forward, policy needs to drive shift from a reactive approach to one which explores the potential of social care data.

Co-produced principles for social care data

The work of the three forums led to the creation of a set of co-produced principles for data in social care. We propose these principles as a starting point to guide future work however, we recommend that these are further explored and developed in collaboration with people who access care and support.

People should only have to tell their story once

Grounded in Human Rights and ethics

Within legal parameters and regulation

Citizen activated and citizen controlled

Shared understanding

Measurable intervention that is meaningful

Groundswell

Notice and avoid risks

Systems should not get in the way

Integration, involvement and interdisciplinary data

Learning and skills implementation

Review and fluidity

Incremental implementation

Prevention and quality

People should only have to tell their story once

The onus should be removed from those accessing care and support to repeat their story and instead be placed on the system to support them. Any work on data in health and social care must be person led.

Grounded in Human Rights and ethics

A rights-based approach should be applied to ensure that work in the social care data space remains grounded in ethics.

Within legal parameters and regulation

Any work on data in social care should abide by existing laws and regulation.

Citizen activated and citizen controlled

Individual citizens decide what happens with their data. This principle should also apply to the workforce.

Shared understanding

Well-articulated definitions should be used to promote understanding. We need to be able to translate between different systems and to be able to rely upon the trustworthiness of data. What data means to other people - collation, presentation and analysis should move from the research space into a routine space of understanding.

Measurable intervention that is meaningful

Data has the potential to make real change even to save lives. Work should shift away from a 'performance' heavy focus to consider 'how do we measure impact?' and 'what difference are we making?'

Groundswell and incremental implementation

Innovation in data can happen on an incremental basis. We spend a lot of time talking about systemic level change yet that has not always come from top down. It is entirely possible to address this challenge one step at a time. Build out proof points and replicate.

Systemic change is like turning a tanker. Instead, this initiative should take a groundswell approach with localised initiatives being supported alongside policy change - #datachangeslives
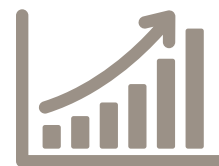
Notice and avoid risks

Those accessing and manipulating data need to be able to understand what it means and the risk of unintended consequences or assumptions. There may be underlying unseen reasons, incorrect or incomplete data creating inaccurate conclusions to be drawn. "Data can also cause you more problems if you're measuring the wrong thing."
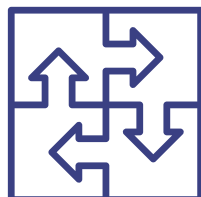
Systems should not get in the way

People will always take the easiest route. Our systems need to make it easy for people to record the information that matters to support data accuracy.

Integration, involvement and interdisciplinary data

The set of principles should be relevant to the whole sector with the point of integration being the person in the system. Involving all interfaces of health and social care provision will ensure that what is developed is fit for purpose. From a care providers perspective, this co-design would also include interface of both system and data and intelligence.

Learning and Skills Implementation

There should be support for those who interact with and use the data systems to upskill. This should include users of social care and support.

Review and fluidity - Principles must not be set in stone

Principles must not be set in stone – they should be reviewed and adapted as we learn and as systems develop. To do otherwise would limit potential.

Prevention and quality

The potential of data should be realised, to promote a preventative approach and quality improvement.

Creating the conditions for change

It is recommended that future work support the articulation of the challenge by separating the 'experience' layer as something independent from the 'data' layer when we consider the social care landscape as these involve different people and different stakeholders. Therefore, mapping the processes and journeys that are involved would help to understand the role of data. In addition, working in clusters or in a place-based way could support change and innovation locally that could evolve to enable national change. Different areas have different levels and appetite for risk and offer the potential for collaboration where interested parties can come together to solve specific challenges.

There is also the potential to make better comparisons across existing systems which could affect policy and practice, as well as explore the potential of the census. Establishing the intent for data collation, interpretation and analysis is also required, for example, in considering the role of machine learning, predictive analysis and data management in achieving outcomes.

The role of policymakers is critical in providing leadership and support in enabling change and the forthcoming data strategy is an ideal opportunity to lay the groundwork in establishing the conditions for change.

Most important of all, creating the conditions for change must place people and communities at the heart where the ethics of data are fully considered on a human rights basis, and where the social care workforce are fully supported and enabled with access the resources they need to ensure that the creation of value from data supports the value we want in our care and support.

Acknowledgements

Appendix

Appendix 1: Speaker presentations

The data forums involved presentations from:

- David Alexander, Mydex CIC, 'A world with citizen held data'
- Jonathon Waldheim, NDS Scotland, "National Digital Platform"
- Chal Chute, Digital Health and Care Innovation Centre. "Between the Scenes"
- Dr Tara French, Scottish Care, 'A vision for technology and digital in social care'.
- Dr Susan Shenkin, University of Edinburgh, 'Developing a data & innovation platform for care homes in Scotland'
  https://www.medrxiv.org/content/10.1101/2020.08.17.20176503v2
- Dr Jenni Burton, University of Glasgow, 'Understanding Scotland's Care Home Population – challenges and opportunities'
- Taffy Gatawa, Chief Information and Compliance Officer at everyLIFE technologies, Enabling Better Care

Appendix 2: Scottish Care data web pages

Data Forums 1 and 2: https://scottishcare.org/social-care-data-forum-invite-3-december/

Data Forum 3: https://scottishcare.org/social-care-data-forum-3-notes-resources/

# Appendix 3: Social Care Data – Practice based examples

Work is being undertaken by CASPA which focuses on hospital to home transitions to ensure that people reach the right destination using simple tools. The work reduced time spent in acute services and gave confidence to commissioners. This example could be applied in other circumstances.

DHI co-design work in Grampian reduced nursing record forms from 42 pages to 1 piece of paper (2 sides) that did everything that the MDT needed it to do. They started with the premise that it should be focussed on what that team required, and to add more information on request. A key step was to remove questions which could be answered by someone in their own home to minimise duplication and effort: https://futurehealthandwellbeing.org/nursingrecords

Data Driven Innovation at Edinburgh University are working on a project in the Lothians to create a national and regional asset of health and social care data. Key to this work is identifying what is meaningful to collect and what can inform service provision. There is a wealth of information around, social care information is disparate. Information that we can combine provides much more potential, to get insights into what interventions are effective, identify vulnerable people. The underlying asset is a project called data log, pulling together information across hospitals right through to social care. Starting in Lothian this project has begun with secondary care information and primary care data and will then be moving on to social care data.
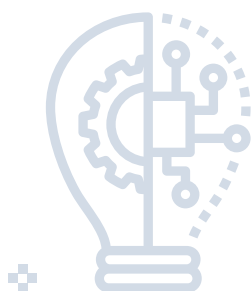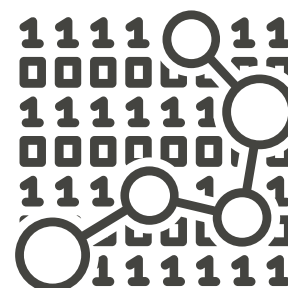
In England, there is a lot of activity around technology shaping the way care is delivered. This put a focus on data and advocacy around use of data in social care. CASPA have been collecting data on impact of COVID on social care, it is now possible to look back at what that data looked like at beginning, the change in data over time, and plotting news and headlines from Government against data. The programme started at the beginning of the first wave and while there was not total coverage, it was initiated by identifying like-minded people who were interested in how COVID was impacting the sector, driven by a need to do something meaningful.

We must ensure throughout that we're not throwing a solution in where there's not a problem.