

# The future of data-driven social care

How can we harness information to care more proactively?



## The future of datadriven social care

The past 12 months have seen a drastic shift within adult social care, as elsewhere, towards far greater and more inventive use of digital technology.

With direct personal contact drastically curtailed, and the health and wellbeing of millions threatened by Covid-19, people working in this most human-centred sector – sometimes pigeonholed as tech-phobic – have improvised impressively at speed.

Enhanced data sharing and analysis have played key parts in this innovation. Local agencies have worked in the teeth of the pandemic to break long-established silos between social care commissioners and providers and the NHS, and deployed technological solutions to remotely monitor, assess and support the health and wellbeing of people accessing services.

But, as a House of Lords Public Services Committee report published in November 2020 observed, progress remains uneven.<sup>1</sup> Notably, central government data-sharing was criticised by one authority as "wholly inadequate", and the committee called for new guidance on how barriers to the flow of information could be overcome.

Department of Health and Social Care (DHSC) proposals for a new Health and Care Bill, subsequently published in February, said the government will legislate to ensure more effective data sharing as part of place-based integrated care systems (ICSs).<sup>2</sup> These partnerships, which are to become statutory, incorporate local NHS bodies, local authorities and other organisations, who will have a duty to collaborate.

1 in 10 experiencing symptoms 12 weeks after an initial positive test.

> British Medical Association, 12 February 2021

Long Covid affected ability to work	80%
Long Covid affected finance	<b>36</b> %

80% of respondents in our survey saying Long Covid had affected their ability to work and 36% said it was affecting their finance. As well as clinical rehabilitation care, some people need ongoing social care. Particular attention should be paid to the impact of Long Covid on vulnerable people, (such as older people with preexisting health conditions) who may not have been captured in research to date and who may be tipped into a state of frailty.

> National Institute for Health Research, Living with Covid 19 - Second Review, 16 March 2021

Their benefits are already being seen in some areas, such as Dorset, where a 'virtual ward' bringing together health and social care professionals has helped cut unplanned hospital admissions – an important step in a county where a potential £230 million hole in the local health economy was identified five years ago.<sup>3</sup>

But the potential role of data across health and social care services goes much further. "[It] will grow in prominence in the months and years ahead, as new digital technologies Directors of Adult Social Services (ADASS) and the TEC Services Association (TSA), which published its findings in March.<sup>4</sup> The commission concluded that few areas have truly managed to integrate technology into adult social care, but that its normalisation during Covid-19 presents a window of opportunity for deeper change. Its report argued for creating better digital infrastructure, granting people more control over their health and social care data, and developing services founded on coproduction and collaboration.

Dorset Council has one of the most advanced systems having calculated in 2016 that a do-nothing approach would create an annual financial gap in the local health economy of almost £230m by 2020/21.

#### ££££££££££££ ££££££££££

Over 3m people worldwide now accessing a form of remote patient monitoring - why hasn't this tripped over into social care?

and artificial intelligence (AI) become more readily available to public service providers," the Lords committee report said. This changing landscape opens up exciting possibilities for improving citizens' experiences of care, by making services more proactive, enabling and responsive, and for organisations to make best use of scarce resources – which could be stretched further by the still-unknown impact of 'Long Covid'.

Questions around how to seize those opportunities were at the heart of a joint commission between the Association of

The potential role of data across health and social care services goes far beyond better sharing. But how exactly can more proactive use of data deliver better choice, quality and control for people who access care and support services, their families and carers, while enabling commissioners to do more with less? How do perspectives vary on where the sector is at, and what the main barriers are to making progress – and what considerations need to be kept in mind as we look to the future?

ADASS interviewed a group of sector experts – including people with lived experience of services, commissioners, providers and consultants – to explore these issues further. This discussion paper is sponsored by the smart technology company Lilli, which is focused on the need to utilise data much more effectively within the social and health care system.

# The adult social care context



and 2035.5



decrease of beds in care homes

18 - 64 year olds receiving support

in their home

The average person's healthy life expectancy is below 64 years, meaning many spend a significant number of years with social care needs.<sup>6</sup>

The UK population of over-65s has increased by a third since 2001. The number of people aged 65 to 79 will increase by nearly 30%, and those over 80 will double, between 2018

Between 2012 and 2020, the overall number of beds in care homes (nursing and residential) per 100 people aged 75 and over declined from 11.3 to 9.6 – a 15% decrease.<sup>7</sup> In 2019 alone there was a reduction of 23,452 care home beds.<sup>8</sup>

The decline in use of care homes is further substantiated by the fact that the long-term support needs of older adults (aged 65 and over) met by admission to residential and nursing care homes per 100,000 population decreased from 658.5 in 2014/15 to 584 in 2019/20.<sup>9</sup>

Falls are the single biggest reason for emergency admittance to hospitals for over-65s.<sup>10</sup> One in three over-65s have at least one fall per year, most of which happen at night.<sup>11</sup>

Pre-Covid, the requirement of care for working-age adults was growing faster than any other age group in the UK. In 2019/20, the number of adults receiving long-term support arranged by local authorities fell from 873,000 to 839,000, with the total aged 18 to 64 – most of whom receive support in their home – remaining steady at around 290,000.<sup>12</sup>

## Talking the talk



The promise of using data as a means of improving social care services has been talked up for years, particularly since the advent of the Internet of Things – the networking of objects that can gather, analyse and act on data.

As of 2020, around 1.7 million people in the UK – and rising – were being supported by some form of tech-enabled care.

> The use of smart speakers as digital assistants, for instance, to manage home environments or remind people to take their medication, is one application that has received significant attention. Discreet home sensors – which can pull in information about motion, light levels,

temperature, pressure and other metrics – have also been put to increasingly sophisticated use in monitoring people's wellbeing and enabling them to remain in the community.

As of 2020, around 1.7 million people in the UK – and rising – were being supported by some form of tech-enabled care, predominantly reactive alarm-based systems.<sup>13</sup> Helen Sunderland, director for local public services at EY, says the picture is often still one of digital technology being piloted, albeit at a decent scale, or bolted onto existing services and rarely integrated into the specification for other types of provision to help truly transform care pathways end to end.

"We talk a good game – with care tech providers we're involved with, we have had interesting sessions and conversations [with commissioners] about the potential

#### "We've got a strategy for the future – but we're at the beginning of the journey in getting that off the ground..."

of assistive technology," she says. "But then specs come out, and it looks like telecare.

"The challenge is real as there are legacy systems and approaches that need to be addressed at the same time as providing the freedom to providers to do things differently," Ms Sunderland continues. "It's a difficult line to tread for commissioners and digital care providers, who often need to partner to achieve innovation and compliance, but occasionally some of the prescriptive aspects of the specification for service elements like response can be prohibitive."

The unprecedented circumstances of the last 12 months have though triggered a genuine change in attitudes, Ms Sunderland notes.

"There have been a number of points in the care pathway throughout Covid where you can see the real impact being more informed can have on how quickly you're able to respond to things, how enabled and empowered you are to do something about them, where that capacity, is where you're sending cases to," she says. "Even before you get into clever stuff around predictive analytics and demand management, just the basics of effective operational management, and the value of multi-agency data, are starting to be better appreciated."

Changes at this foundational level offer clear benefits, explains Alison Tombs, the assistant director for wellbeing and assessment at North Tyneside and an ADASS trustee. Her council recently signed up to the Great North Care Record, an integrated repository for 3.6 million people's patient data.

"Interoperability shouldn't be such a big challenge," says Ms Tombs. "We all have different systems, but it links us into sharing that data," she explains of the Great North Care Record, which brings together NHS bodies, councils and universities across the North East and North Cumbria.

But Ms Tombs acknowledges that making more sophisticated use of data is one part of a puzzle waiting to be unlocked. "We've had lifestyle monitoring services in place, but haven't utilised them as much as we could have – and our service has been analogue based, though we are moving over to digital," says Ms Tombs of her council. "We've got a strategy for the future – but we're at the beginning of the journey in getting that off the ground, and being clear about what kind of technology can support people's needs in terms of their social care outcomes."

# Changing cultures

#### So what barriers have stopped adult social care commissioners – and the providers that work with them – putting data to more effective use?

The influence of organisational culture should not be underestimated, says Julie Ogley, the director of social care, health and housing at Central Bedfordshire Council. She notes that her authority has had "a couple of bashes" at moving forward with assistive technology solutions without really gathering momentum.

"We're quite used to using smartphones and smart speakers to run our daily lives – but not our business lives."

> "I started a discussion in my council several years ago about why we behave differently [around technology] when we come to work," explains Ms Ogley, who was ADASS president during 2019-20. "We're quite used to using smartphones, smart speakers and what have you, to run our daily lives – but not our business lives."

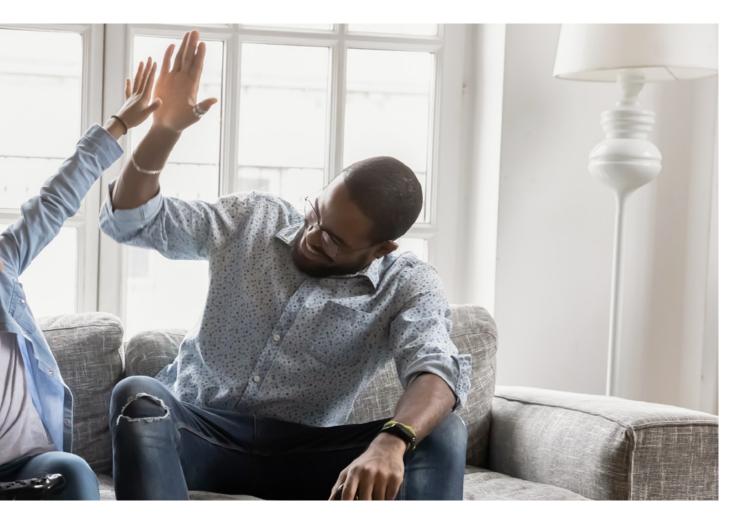
> Care-specific tech put in place by councils has often been "cumbersome, bulky and ugly, and generally doing things that the rest of the world has been able to do for years," observes Anna Severwright, a convenor at



the Social Care Future network who has firsthand experience of social care services.

Ms Ogley adds that at a big-picture level, adult social care bodies have been "generally nowhere near" their health peers, in terms of using data to understand and predict different groups' outcomes and service needs. "I've listened to health colleagues talk about population health management, and we simply don't have the same level of analysis in social care," she says.

Councils, agrees Iain MacBeath, the strategic director of health and wellbeing at Bradford council, have yet to fully engage with "the art of the possible" when it comes to digital technology.



"I think we need to enable, facilitate social workers to encourage families to get more into the sort of tech that's available, but crucially we haven't yet got our head around how big data could help us"

Iain MacBeath

"We, social care and councils, generally do not place a value on good business analysts," says Mr MacBeath, who is also an honorary treasurer for ADASS. "It's knowledge about IT, and big tech, and systems, but it's also that curiosity to know enough about social care to then draw out what the data could tell us, come up with hypotheses and test those with practitioners – quite a specific skill set."

The latter half of that person specification, reckons Ms Sunderland, is arguably the most important. "I think the skills to deal with data and analytics are out there," she says. "The challenge is more like, 'OK, so what?' What do you actually do about [what you find]? How do you embed it into your way of working?"



# Getting in early

They may be in the minority, but some councils have – thanks to councillors willing to take a risk and invest – made progress in this direction, says Mr MacBeath. He suggests Hertfordshire, where he was previously the director of adult social care, has been one such authority.

By 2020, Mr MacBeath says, analysts at the council – which already owned homesensor hardware – had "cracked" algorithms relating to behaviours displayed by people with dementia, and with urinary tract infections (UTIs).

"These are two key scenarios where you can intervene early with medication and prevent people from getting worse for a while," he says. The authority shared its technology with a commissioned care provider, which it pays to respond on a 24hour basis to changes in people's behaviour rather than waiting for council staff to get into work. An evaluation recorded clear benefits stemming from the council's investment in in-house analytics expertise.<sup>14</sup> Staff felt the technology could be useful for 40% of people accessing services – citing potential positives including being able to discharge earlier from hospital, and create care plans based on better evidence – while carers reported greater peace of mind. But with many local authorities lacking the relevant in-house expertise, money or political will to come up with such solutions from scratch, developing ways to pool knowledge regionally or through ADASS would be a step forward, says Mr MacBeath.

That will take time, he notes, adding that having access to reliable, third-party offthe-shelf options – the lack of which was a motivation for Hertfordshire's experiments – could be a game-changer for many.

# From reactive to proactive data

That shift is on the way, according to Gren Paull, Lilli's chief executive officer. Smart technology, powered by machine-learning algorithms, is becoming increasingly adept at monitoring behaviours to spot patterns and trends, he points out.

Behavioural 'flightpaths' can now be modelled for people with different conditions, with professionals alerted when their actions begin to deviate from their 'normal' patterns. This enables actions to be taken or plans to be reviewed, responsively and before crises occur.

Smart technology, powered by machine-learning algorithms, is becoming increasingly adept at monitoring behaviours to spot patterns and trends.

> "We have been having conversations with several local authorities, and with care providers, identifying what they want to know about the behaviours of people within their care for them to make betterinformed decisions about care packages and provisions," says Mr Paull. Given the difficult financial position of many local authorities, and their resource constraints, "they have welcomed this approach and the considerable benefits it can bring to their day-to-day tasks", he adds.

Expanding on the scenarios discussed by Mr MacBeath, Mr Paull sets out several use cases in which this kind of technology can be beneficial.

"There's a real example, a gentleman who was 70, with diabetes, his parents had recently died and he was their number one caregiver," he says. "Over about 10 days, he started going to the toilet more, then became severely dehydrated – this wasn't picked up, because he wasn't being monitored, and he ended up collapsing, an ambulance being called, and having a stay in hospital with kidney stones.

"The council we're working with said this one-off episode has cost £15,000," Mr Paull continues. "It could have been picked up – the data doesn't know what to do, but it can tell you that patterns and behaviours have changed. If it had been identified earlier, this situation could have been avoided altogether – with a significantly lower impact and cost to primary care, social care and this man's life."

Mr Paull adds that by tracking movement and heart rate, the technology can map out individuals' physical rehabilitation pathways. Meanwhile, the extent to which people are eating and drinking independently can also be modelled, helping to inform whether associated visits from domiciliary care providers be stepped up or down (see case study, page 12).

# A deviceagnostic future

In contrast with care technology stereotypes – clunky grey boxes that do not interact with one another, and must be reacted to by humans – the type of setup described by Mr Paull relies on small generic sensors. Dashboards are accessible from computers and mobile devices, can email summary reports, and will soon directly integrate with electronic case management systems, meaning they sit inside health and social care professionals' existing information ecosystems.

"Integration is more than just building partnerships around service providers and commissioners, it's also about how the systems can integrate better and more effectively"

> "Moving from a product base to a networkbased system is certainly the way forward for players in this space," says Jeremy Porteus, the director of the Housing



Learning and Improvement Network. "One of the facets of a network solution is that there has to be interoperability.

"Integration is more than just building partnerships around service providers and commissioners, it's also about how the systems can integrate better and more effectively," Mr Porteus adds. "So housing, health and social care are blended in a way that different outcomes can be identified, rather than having a patchwork of three or four different pieces of kit."



The near future is likely to see a further weaning-off from proprietary hardware, as smart devices able to provide relevant data – phones, watches, fitness trackers, lightbulbs – proliferate. Smartwatches, for example, can already measure blood pressure and oxygen levels as well as monitoring heart rate and rhythm.

It's a development that's not before time, says Ms Ogley, who notes that she raised the issue, while president of ADASS, of why major consumer technology players were not more involved in social care. "Technology needs to look normal, attractive, and fit into our daily lives, so [I couldn't understand] why care tech firms weren't in partnership with those types of providers," she says. The migration process "must be linked back to digital inclusion, because not everybody's got smartphones and things", says Ms Sunderland. But, she adds, this picture is changing rapidly – and increasingly, people coming into contact with social care services will have grown up with technology.

"[The issue will be], 'Is it OK that the public sector funds buying someone these devices?'," she jokes. "Frankly, if it saves thousands per week on home care fees, yes it is – although whether certain parts of the media appreciate those nuances is another question."



Case study:

#### udy: Dorset council

Dorset is one of several local authority areas to have experimented with data-based technologies. The council has recently enrolled on a new trial focused on gathering data from users, and creating algorithms around their daily life through unobtrusive software to enable earlier-stage prevention of potential mishaps.

Dorset has explored the use of data to assess whether people discharged from hospital are becoming increasingly independent. For example, if someone is receiving three visits a day, activity monitoring systems can show us whether any of those visits can be reduced e.g. a lunchtime visit. Evidence produced for the council suggested this alone could save it up to £4,000 per person annually, while enabling someone to remain at home rather than moving into residential care could save £30,000 over a year. Claire Collett, an occupational therapist in the council's tech-enabled care team, says the potential benefits both to commissioners

Enabling someone to remain in their home rather than moving into residential care could save £30,000 over a year. and individuals in receipt of services are clear.

"It's cost-effective and there are opportunities to make a system-wide impact - we've got our partners, our CCGs and the NHS, and we've got the opportunity to look at how someone can be discharged early and monitored, the system is simple and unobtrusive." says Ms Collett. "We are very much looking more around the preventative side of things - if something's happening to someone, if we can get in early and put some enabling strategies in place, we know that that will save us and our partners money. We're also of course looking at people's medical conditions not worsening and, sometimes, potentially saving someone's life. From a TEC OT point of view, I'm very mindful of the impact on the person's outcomes and their ability to retain independence, choice and control these values are also held highly within the council's transformation programmes."

Where systems identify a possible deterioration in someone's health or wellbeing following discharge, the aim is to respond via GPs, district nurses or community rehabilitation teams to prevent readmission. But Ms Collett adds that the technology can also help people already accessing the council's adult social care services.

"We've got one couple where the gentleman is looked after by his partner, who struggles with alcohol," she explains. "When she



starts to spiral downwards, she doesn't look after him so much and we get to a crisis every three or four months where she's admitted to hospital, and he needs more care – typically a four- to six-week package, three or four visits per day.

"In a situation like this, if we could see household activity changing early, we could put in some other support to help prevent her from being admitted, and him needing such a huge amount of care," Ms Collett continues.

The council has historically used activity monitoring systems as short-term

assessment tools, she continues, but a more sophisticated analysis of people's circumstances will lend itself to longer-term use. "We want to be able to say to health partners, 'This is working well, because we know that over six months, we have prevented this amount of people having to go back into hospital," Ms Collett says.

"We've always funded technology that reacts to something that's happened but we've not been able to say, 'Why did this happen?'," she adds. "We want to look at what is happening before a person has a fall. Technology that can do that is the future."

# Seeking consent and providing explanations



#### Gathering and seamlessly sharing social care data via devices that are unobtrusive, or designed for consumers, feels like an obvious win.

It can make life easier for workers and senior managers alike, and remove the inconvenience – and in some cases stigma – people who access care and support services can feel when dealing with unwieldy chunks of care tech.

But, points out Baroness Hilary Armstrong, the chair of the Lords Public Services Committee, innovation in this area carries its own responsibilities. "It demands that people are open with their citizens' groups, their consumer groups, about what's going on, in terms of sharing data," she says.

Both Ms Ogley and Mr Porteus agree, arguing that social care organisations and their partners in health and housing must become much better at educating people accessing services as to how using their information can facilitate better, more preventative care.

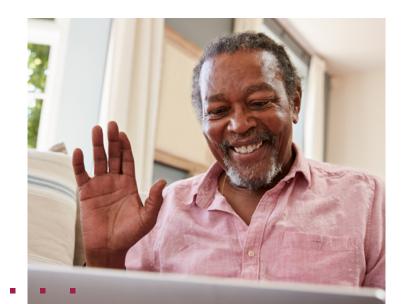
Too often, adds Ms Severwright, public bodies' use of data can feel more focused on saving money or serving their interests rather than those of individuals. "To me, it's about asking why?" she says. "Why are we collecting the data, and how can we use it in ways that enable people to have more control over their care?

"It's great to keep people safe and monitored, so we know they are taking medication [and] don't have a fall," Ms Severwright continues. "But we need to be also looking at how technology can boost people's wellbeing and help them live the life they want to live."

As a starting point, Ms Severwright – who has chosen to use a smart speaker as a personal assistant – says people should not have technology they are uncomfortable with foisted on them. "Often, I think if the sector thought to include [people who use services] when designing and commissioning them, you'd waste less money on things that don't work well – and it could go to things that do," she adds.

## Rethinking commissioning

Reimagining commissioning, to be more inclusive and creative, formed a key part of recommendations made by the recent TSA and ADASS commission. Its report advocated that local authorities should encourage consortia of care and technology providers to come together with the aim of harnessing data to deliver more proactive, preventative care. The report also envisaged that people with lived experience should play a key role in shaping the resulting services.



"We're not asking people what would be useful for them – we're always in such a rush to tender care contracts," says Mr MacBeath. "We could ask homecare agencies to partner with [a data-driven care technology company], collaborate and come up with a joint offer instead we buy what we've always bought." Ms Tombs' council plans to trial an arrangement with a provider whereby some contacts are made digitally rather than in person. She says she hopes the resource savings enabled by better use of data could ultimately "free up people" to do other work – a point that's picked up on by Ms Severwright.

"It's not necessarily about replacing staff, but perhaps enabling them to be used in different ways," she says. "I think what worries people is that we can end up within a situation of not seeing anyone, because the tech is making sure we're alive every day and taking the tablets – but the human side of care is still really important."

Moving away from commissioning traditional time-and-task models towards outcomes-based ones will also present a puzzle that public authorities looking to demonstrate the benefits of investing in preventative, data-driven solutions must find ways to solve, says Ms Sunderland.

"It's easy to monitor time-and-task," she says. "So it's almost like, well it's not that broke, so don't fix it – even though from an outcome perspective, you know there is much more potential.

"I think there's a huge opportunity here," she adds. "The challenge is time to think through how you get the best out of it, capacity to invest, and the ability to work with partners who can broker a deal across providers and commissioners that works for everybody."

"User feedback is a very important aspect, so we've recently created a digital service that allows people to enter information online relating to providers. That has been really successful – we've had a vast increase in the number of bits of user feedback we receive."

#### The regulator's view

The Care Quality Commission (CQC), which under plans included in the government's NHS reform white paper would again assess councils' adult social care services as well as providers', has issued several pieces of recent guidance around digital technology.

Most recently, in February the CQC's 'Enabling innovation and adoption in health and social care' paper set out six principles around innovation, which includes a focus on co-production, organisational culture and the impact and outcomes of change.<sup>15</sup>

The aim is that using analytics to deliver a more real-time picture of the state of services will enable support to be focused where it is needed.

> "Despite the pandemic's challenges, we have seen the health and care sector adapt at scale and pace through this time, with many planned innovations brought forward, and greater sharing of information across the sector," says Mark Sutton, the CQC's chief digital officer. "We are looking to embrace available technology opportunities to improve how we work, how we regulate." The CQC expects that providers will be doing likewise, he adds.

The CQC's forthcoming strategy is built on four themes that together determine the changes the organisation wants to make. One is around "smarter regulation", Mr Sutton says. "People don't want to sit and read a 500page report – they want to say, 'Show me the quality of services 50 miles around me, and I'm interested in these particular indices, and show me those on a graph," he says. "That's what we want to be able to provide – an up-to-date version, a view of quality and risk that exists within providers."

The aim is that using analytics to deliver a more real-time picture of the state of services will enable support to be focused where it is needed, while keeping the public better informed. The CQC is already gathering provider data from a range of sources and is developing a digital interface to enable organisations to communicate and deliver information, either through a portal or via an API.

"We're also looking to reduce burdens on providers by creating an automated means of data transfer," continues Mr Sutton. "But we take data from lots of other sources too – user feedback is a very important aspect, so we've recently created a digital service that allows people to enter information online relating to providers. That's something that has been really successful – we've had a vast increase in the number of bits of user feedback we receive. Designing and implementing a new way of working takes time and we want to get it right. We'll continue to engage with stakeholders to implement our strategy from May. "



#### Final word from Lilli:

The uptake of technology in the wake of the Covid-19 pandemic among the health and social care systems, to assist both people accessing services and employees, has been a welcome development.

But there are still barriers that must be addressed to ensure this shift to a different way of thinking is not simply temporary. The introduction of ICSs will help support this change, but social care services must not wait to address their own TEC and datasharing constraints – strategising for the now, as well as the future is key.

Councils must also engage with 'the art of the possible' and invest in business and staffing infrastructure that supports gathering and analysing data.

> Many of us have embraced smart tech within our personal lives, possibly because of how seamlessly it fits into our routines, but there is a more cautious approach for business use. However, data-driven, tech-enabled care can help providers

make better-informed decisions about patient needs, thus facilitating quicker responses, and ultimately saving more lives. By engaging with reactive and unobtrusive technology and moving away from the 'clunky' exports of the past, health and social care resources can be supplemented, enabling commissioners to do more with less.

Councils must also engage with 'the art of the possible' and invest in business and staffing infrastructure that supports gathering and analysing data - and changing or implementing procedures based on their findings. Tech must not, and should not, remove the human element, but work alongside it to improve quality and timeliness of care, while potentially supporting a more cost-effective solution for providers. Lack of education, both on data safety and software efficacy, and collaboration have been identified as barriers to success, but are imperative to boosting TEC uptake among colleagues and people who access services.

The impact of Long Covid on the health and social care system is still unknown, but coupled with an ageing population there is further need to bolster the health and social care system and introducing TEC and data-driven decisions to everyday care could help alleviate this strain.

#### Key takeaways

- The social care sector as a whole needs to build on the culture shift achieved during the pandemic and embrace the potential of data – and digital technology more broadly – to improve services.
- Local authorities should share expertise and good practice around data sharing and analysis within social care, so that those lacking the resources to develop their own solutions from scratch can learn from peers who do. This could be done at a regional level or nationally via ADASS.
- Social care, health and housing organisations should be enabled to work together to integrate systems so that all can benefit, including through the possibilities offered by data-analysis products that do not depend on proprietary hardware.
- Commissioning bodies, and care and tech providers, must include citizens in the design of products and services at an early stage, be transparent about how their data is used and set out clearly how it can make care more preventative and less reactive.
- Public authorities should involve tech as well as care providers when commissioning care, enabling services to be designed that fully incorporate digital and data solutions.

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