NEW DIALOGUES
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Directors of adass adult social services

BETTER CARE THROUGH DATA

How could better use of health and care data enhance the quality of adult services?

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BETTER CARE THROUGH DATA

With the use of data analytics becoming increasingly important to how businesses provide the best service for their customers, ADASS and Capita One organised a roundtable debate with several adult services leaders to discuss what potential data has in improving health and care

The potential benefits from the effective use of data in health and social care are hard to overstate.

Better collection and use of data could be nothing short of revolutionary - enabling a system where threats to individuals' wellbeing are spotted and addressed early, care is planned more effectively and the disconnect between services banished.

Yet realising this data-enhanced future for health and social care is not straightforward despite the rapid development of technology in the past few decades.

It is fundamentally important that citizens are actively engaged in how their data is used and that local areas demonstrate trust in the use of this data. This needs to be at the forefront of activity by organisations.

At the same time there are challenges to overcome around the practicalities of bringing such information together from across individual organisations and, importantly, making sense of the data in a way that helps improve the way services are delivered.

With all this in mind ADASS, with support from sponsor Capita One, organised a roundtable discussion in London in July bringing together representatives of local government, adult social care services and the NHS to examine the challenges and promise of data.

RICH INSIGHTS

Roundtable chair Grainne Siggins, director of adult social care, health and housing needs at the London Borough of Newham, kicked off the discussion by noting how adult social care was now waking up to the value of data in part out of necessity.

"Adult social care has started to be more interested in data and data sets," she said. "Historically, I don't think there was a significant amount of attention paid to data other than national submissions, but council budgets are being squeezed, health system finances aren't increasing, and we have significant demands on services it is so important that we use our information, data and an analytical approach to inform the way we commission and invest in services."

Mark Golledge, the health and care digital lead at the Local Government Association, agreed that social care was now paying more and more attention to data. "We're seeing a shift towards population health management and a more effective use of data across local areas, particularly in understanding an individual's journey across the whole health and care system or evaluating the impact of health and care services," he told the roundtable. "There are a number of local areas that are now bringing together health and social care data at system level to help them to better understand what activity is happening across the system and use that to inform planning.

"Whilst there is evidence of innovation this needs to be balanced against the need to safeguard and protect people's information. Whilst the information being used is information that does not identify an individual, there is a need for clear controls around the data to reduce any risk of re-identification. The need for close working both between organisations and with citizens is therefore essential."

One organisation that has been bringing health and social care data together is Tower Hamlets, a multi-speciality community provider vanguard site, where health and care partners (Tower Hamlets Together) have worked together to link health and social care data, which is helping them to better understand how groups of people interact with health and care services, as well as considering how to address the wider determinants of health and care.

"We are just beginning to use it to help understand patterns of health and care use, building our intelligence to design more effective and productive pathways and services going forward," Richard Fradgley, the director of integrated care at East London NHS Foundation Trust, which is a partner to Tower Hamlets Together, told the room. "It will also give us really rich insights into how wider determinants of health and care are associated with patterns of health and care use."

THE BIGGEST BLOCKER

Fradgley offered the roundtable some practical examples of how the data has been used and the benefits it has delivered. "Last year we undertook some early stage work on how mental health conditions are associated with health and care demand across the system, looking at the use of hospital services by people with and without mental-health problems and long-term conditions," he said.

"At this stage we only had about half of the system spend in the data set but it was nevertheless very interesting – for example, we found the 2.3 per cent of residents known to secondary care mental health services drive 25 per cent of the system spend, including mental health, and the 11.2 per cent of the population on primary care registers for mental ill-health and learning disability drive 42 per cent of the system spend."

This autumn, Tower Hamlets Together anticipates further developing this work so to better understand how adults with mental health or learning disabilities interact with health and care services, and where there may be opportunities to improve outcomes for people.

Tower Hamlets Together is now working on expanding the data set to include as much of the system spend as possible, and in the autumn it is anticipating working on a much fuller and granular analysis of how mental health and learning disability are associated with system spend.

"We will also be working with health and

care practitioners to develop an evidence-based impact model of how to start to work to reduce the spend and improve outcomes for people and populations – conceiving of preventative integrated mental health and wellbeing services as a system enabler," added Fradgley.

The task of creating the data set has, however, not been without challenge, Fradgley told the roundtable. Tower Hamlets has spent significant time ensuring that the right safeguards and controls are in place to keep the information safe and secure.

One of the biggest challenges was getting the information sharing and governance arrangements right. "A lot of energy has been put into it over a number of years," he said. "Whilst we now have all the required arrangements in place, it has been complex and could not have been done without really proactive and committed leadership and partnerships across commissioners and providers and primary and secondary care and the expertise of our commissioning support unit."

Barbara Nicholls, director of adult social care at the London Borough of Havering, felt that people cite data protection and information governance as a reason not to share. "Information governance and issues around data protection are often, in my experience, the biggest blocker between sharing data and patient-level information across health and social care," she said.

Siggins felt that challenges to information sharing might be less intimidating than they appear. "Sometimes it might be down to the local advice given because people are saying that this is possible, so long as the approaches are carefully and thoughtfully worked through," she said.

Golledge added: "As long as organisations carefully think through what challenges they are trying to solve through the use of data, are transparent and engage the public around how their data is used, and have the necessary controls in place then this will really help in seeing such initiatives succeed."

PERSONALISED CARE

Another initiative seeking to bring health and social care data together is underway at NHS Digital as part of its Personalised Health and Care 2020 programme. "This is a cohesive set of about 33 programmes," said Jackie Shears, programme director at NHS Digital. "The area around data for research and oversight is made up of three programmes, one of which is how we collect data from health and social care. The second is the platform that brings it all

WHO'S WHO ON THE ROUNDTABLE?

NICK CLARKE, social care transformation lead, Capita

RICHARD FRADGLEY, director of integrated care, East London NHS Foundation Trust

MARK GOLLEDGE, health and care digital lead, Local Government Association

SARAH MCCLINTON, director of adult social care, London Borough of Camden

NICOLE MINERS, business development director for social care, Capita One

BARBARA NICHOLLS, director of adult social care, London Borough of Havering

JACKIE SHEARS, programme director, NHS Digital

GRAINNE SIGGINS, director of adult social care, health and housing needs, London Borough of Newham (roundtable chair)

DAVID WATTS, service director for adult social care, City of Wolverhampton Council

together and the third is about innovative uses of data, developing sophisticated analyses and making intelligence available in innovative ways."

As the roundtable members had reflected, Shears reminded people that this needs to be set in the context of a programme about public trust and security which is also a fundamental part of Personalised Health and Care 2020.

Central to the vision of transforming the collection of health and social care data is the creation of an approach which enables near real-time submission of small modules of data that can be anonymised and linked to create an integrated view of activity.

> *"We wanted to take account of the way data is captured in social care"*
>
> **JACKIE SHEARS, PROGRAMME DIRECTOR, NHS DIGITAL**

"We are very keen to make sure that in producing and designing this architecture it isn't health focused with social care bolted on as an afterthought," said Shears. "One of the things we wanted to do when designing the architecture and its principles was we do so in a way that takes account of the way data is captured in social care."

Shears highlighted that NHS Digital is closely working with local areas that are using data across health and social care. NHS Digital is keen to be supporting local health and care organisations and is working with a number of them on the practical steps needed to gain insights from the use of such data, she added.

'FREE TEXT'

One challenge is that some information within social care is collected as free text rather than as coded data. The emphasis in social care is that care plans are developed based on the needs of an individual and so are personalised. The medical approach to coding information based on condition is not the same approach as used within social care.

The freedom that free text offers the people recording the information can present challenges and there are fewer standards for the way information is recorded in social care. "Gaining benefits and insights from information across areas is possible but only if everyone is recording the same things in the same way," said Shears.

Nicholls, however, felt that the free text issue was "a red herring" and that social care had plenty of structured data to call on. "I'm surprised that the pushback has been that social care likes to collect free text because we have collected all manner of data over many years in terms of what we report into national bodies including the Care Quality Commission during the Annual Performance Assessment days and continuing now with other annual returns," she said. "There is data we collect that is very standardised."

DATA BEFORE QUESTIONS

But even when just using standardised data, the task of selecting the core data for social care to collect and share is fraught with challenge, Siggins said.

"In London we had this big debate about whether we could create a core data set that we recommend people capture for planning for the future," she said. "There were so many different views about what the core data set was and what question it was that we were trying to answer that we never actually got to a firm agreement. Yet, we were able to agree smaller bite-sized questions relating to bed-based care, for example, that we're then able to focus on specific elements of data. I wonder if it is such a good thing to have a core data set when we are pushing to have things personalised."

Shears highlighted the differences between health and social care: "We are relatively lucky in that there are a lot more data standards in health than there are in care, but what we've ended up with is hundreds of individual data sets and the burden of that on the health sector is immense.

"I wouldn't suggest that social care needs to go down that road. What we are trying to do is stand that on its head and say, rather than collecting data based on the questions that you want to answer, work out the data that is generated as an individual moves through any part of the health and care system. The idea isn't to determine the questions you want answered, the idea is to determine what data we should capture and flow to enable valuable analysis of activity and to ensure clinicians know all the relevant information about an individual."

The other advantage, she continued, is that if you decide later down the line that another item of data would be useful it should be relatively straightforward to update the IT system so that it starts to draw in that information too. Shears added that the differences between the systems of different social care IT providers should not be a barrier either since there is a "relatively helpful degree of consistency" across the systems.

DATA POLLUTION

Nick Clarke, social care transformation lead at Capita, told the roundtable that as we move closer and closer to developing more joined-up data sets across both health and social care to inform better quality integrated decision-making, action will be needed to prevent poor quality data being inputted and impacting the analysis generated from the data.

This equally applies to both adult and children's services.

"There's a tremendous amount of data out there being captured across health and social care but sometimes the quality of that data isn't particularly great. Ultimately, this

"The predictive model is taking off, the question is how accurate is it going to be?"

GRAINNE SIGGINS, DIRECTOR OF ADULT SOCIAL CARE, HEALTH AND HOUSING NEEDS, LONDON BOROUGH OF NEWHAM

impacts the ability of professionals to make the best decision each time," he said. "Over the last three to four years, we have worked with a number of local authorities across both adults and children's services. In many instances, when we have received and reviewed datasets, it is clear that some important information is either inaccurate or missing. Examples being individuals who would appear to be on residential care packages, fully funded by the local authority, but which are less than £100 per week. Individuals open to a service who appear to be in residential care, supported living accommodation and receiving personal care at home all at the same time. Children who appear to be on a current child in need or child protection plan but which actually ended years ago.

"Ofsted have noted, in many recent inspections of children's services, that poor quality recording of information is impacting the ability of professionals to deliver the best outcomes for children and to identify children and young persons' most at risk. We believe this equally applies to adults services," he continued. "Whilst typically there is no quick fix, the importance of getting this right cannot be overstated. Clear and accurate information that allows professionals good visibility around what is happening to an individual and the wider family unit gives professionals the best chance of making the right decisions and helps deliver better outcomes."

Poor quality data is a problem in many services, noted Sarah McClinton, director of adult social care in the London Borough of Camden: "The national acute services data set for example – that's notoriously unreliable in terms of the codes that are used. There are issues about the data quality sometimes and that does, I think, in some councils, relate to austerity and back office functions being stripped out."

AUTOMATED ANALYSIS

The roundtable also heard how City of Wolverhampton Council has been combining social care and secondary care data sets so that it can, among other things, examine the cost of social care before and after admission to hospital as well as the cost of that admission. David Watts, the service director for adult social care at Wolverhampton, said the next step is to import data from primary care so that they can start to understand what is happening in primary care prior to a patient being admitted to hospital.

Longer term, Watts envisages a data system for health and social care that would not only let services analyse the data but actively alert services when an individual's situation may be about to deteriorate so that they can intervene early.

"I'm really interested in how we use data to automate things locally so that, rather than having to analyse it, you can use it to trigger interventions locally," he said. "So you've got a patient profile that gets tested against an anonymised national or local data set and that acts as a trigger for your GP to say we've got some really good information that may help you based on your health condition, your age, the way that things are presenting.

"One of the challenges we have in trying to do this is understanding the art of the possible around the data that we've got. I think it's just because it's all very new and we don't understand the inter-relationships

"It's worthwhile for local authorities to tap into universities for assistance"

NICOLE MINERS, BUSINESS DEVELOPMENT DIRECTOR FOR SOCIAL CARE, CAPITA ONE

between them or the data set just isn't big enough for us to be able to say if that is a local trend that enables us to do something and focus our commissioning on getting a preventative service in there. Until we have got a national data set we can test our local data sets against you're making assumptions and best guesses."

An advantage of having a system that automates much of the analysis is that it will assist staff in making more timely and swift decisions and free up analytical time to be spent on other key activities.

"I want it to almost feedback to us that, for example, a person who has dementia who has a history of falls engaged with a voluntary sector organisation and we've seen a drop down in the number of hospital attendances for that person as a result of the work that the voluntary sector organisation undertook. It's then evidence of why it's worth spending that pound in the voluntary sector," said Watts. "I want the system to tell me that because I don't have that analysis capacity within my organisation. That type of capacity was first to go when austerity kicked in as it's not the activity that you have a statutory responsibility to deliver."

ANALYSTS WANTED

Fradgley agreed: "Our analytic capacity and capability isn't really pointing in the right direction at the moment. As a provider a lot of our analytic capacity is focused on feeding contracts and contract reporting, rather than focusing on what really matters."

"I wonder if it's more capacity than capability," McClinton said. "If I think about what resources we have in Camden there are some very smart people working in our public health teams and in other teams. So it's not that there aren't skills around, but it's about having sufficient availability of those skills and being able to task people with the right tasks."

Could software tools or partnerships with universities plug the gap, asked Nicole Miners, business development director for social care at Capita One.

"Universities have been supporting councils in Scotland," she said. "For example when implementing policies to support self-management, a PhD student in Stirling investigated the process and outcomes. It's worthwhile for local authorities to tap into universities for assistance."

Members of the roundtable saw potential in working with universities, although additional controls would be needed around the use of this data, but they also felt that the need for analytical staff within councils remains.

"We actually see a lot of local areas that have input from public health analysts that are more heavily involved in some of the population health management approaches, but a number of local authorities are also working with universities," said Golledge. "There is technology available but it's not just about the technology, you've got to have the mindset and you've also got to know what questions you're asking and work closely with commissioners and the people in the services around this."

Another important factor in making the most of data is leadership, Golledge added: "Our experience is that there is a need for clear leadership from across organisations. It's also really important to have active engagement from across those organisations involved in the work. The technical platforms and infrastructure are already there and, yes, there are some things needed to support that, but a lot of it is about having that sense of vision."

Golledge also pointed out that most of the successful projects start small and build up over time. "Having a clearly defined scope and understanding of what you are seeking to do and why is really important," he said.

PREDICTIVE MODELLING

Despite the challenges in building the data sets and analysing them, there was consensus around the table that ultimately such data could open the door for highly effective and personalised early interventions that prevent individuals reaching crisis point by predicting their needs or risks in advance.

"The predictive model is taking off, the

question is how accurate is it going to be?" said Siggins. "That's going to be tested over time. At the moment we are looking at what are the triggers for somebody becoming homeless in their lives and thinking about what vulnerability means as vulnerability can mean different things to different people at different stages of their lives. This data is not just older people with health conditions, it's younger adults going through transitions stages in their lives - losing their jobs, potentially losing the roof over their head. What interventions can we do as a system that might prop those people up at a time of crisis to stop them going into a spiral of decline and potentially using a whole raft of services? Identifying those predictors is quite difficult but the ability that a data warehouse might give us to understand our population better as whole systems is going to be important going forward."

Wolverhampton is already starting to use data to help head off problems early, said Watts. "One of the things we are trying to do as part of bringing together our secondary care and social care data is to enable proactive calling based on people's attendances at hospital," he said.

"For example, people with breathing problems at particular times of the year. Just before that time of the year comes around again our contact centre will start doing some proactive calling around how you can keep yourself well by using NHS 111 or planning ahead to make sure you have the right medications. We haven't got it cracked yet but we're working out how we can do that. That's where I rather the system effectively said to my contact centre these are the people that you need to be phoning this week based on previous activity and these are the conversations you need to be having with them."

But predictive models are only as good as the raw data they are moulded from, noted Golledge. "When we identify people at risk of an increasing social care need the challenge is that risk was defined by people who were already known to social care, so the biggest driver of that was that you have had a social care need in the past," he said.

BEYOND THE SYSTEM

Local authorities will need to find ways to expand their data beyond those already in the system if the full potential of predictive modelling is to be realised.

"I'm interested in how we use data to automate things so that it can trigger interventions locally"

DAVID WATTS, SERVICE DIRECTOR FOR ADULT SOCIAL CARE, CITY OF WOLVERHAMPTON COUNCIL

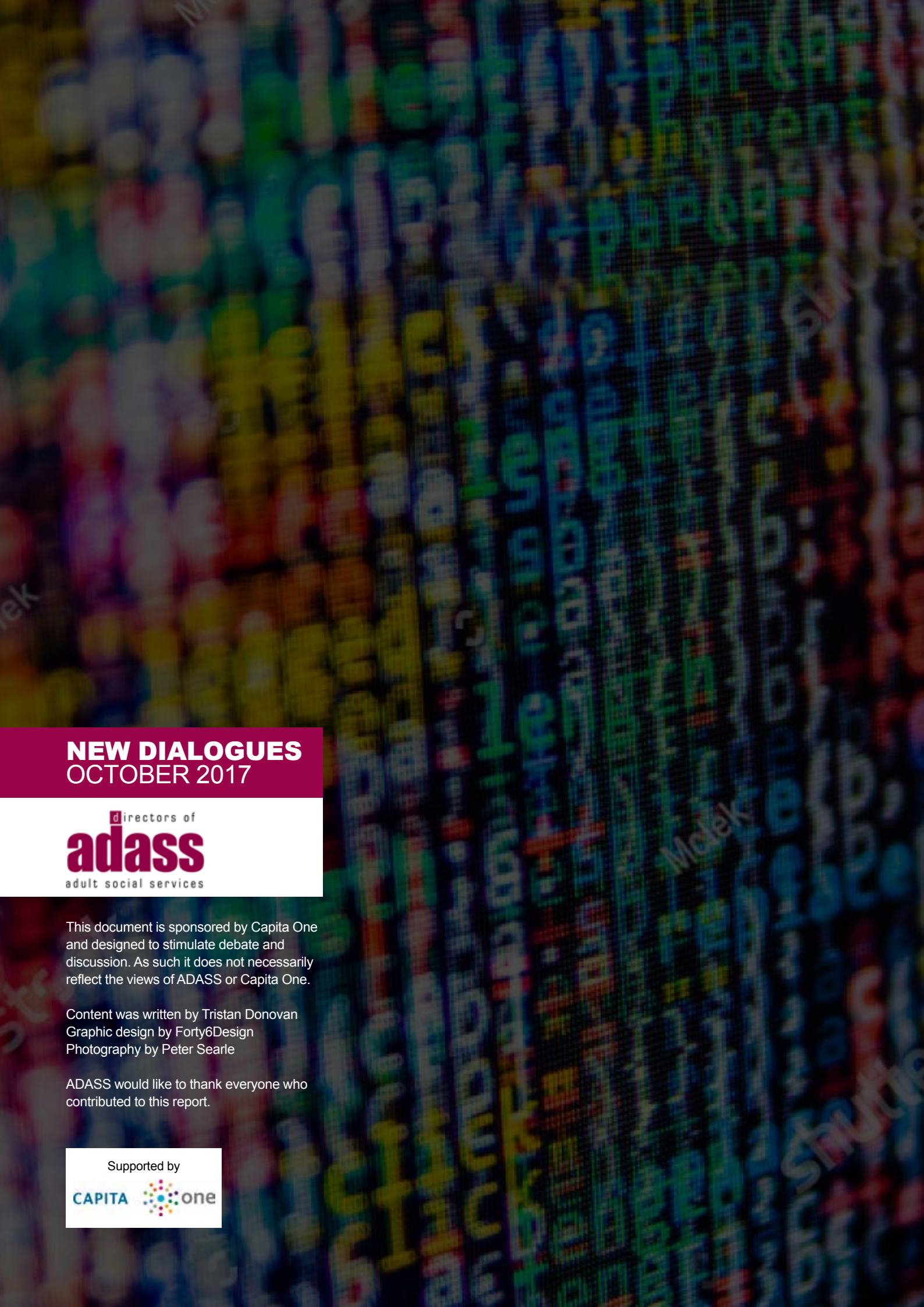
"We've started to have conversations with a few localities about how do we shift more; perhaps, identifying people at risk of losing their independence or wellbeing," said Golledge. "There's a question about what do you define as independence and wellbeing, and then there's a question what data indicates some of these broader risk factors. It's still relatively early days but we want to focus on prevention and early intervention where that is possible so as to help people be independent and well connected in society for as long as possible."

Sometimes it can be better to think small said Capita One's Miners: "What they tend to do in Scotland is keep the data small. At the moment it's like boiling the ocean when it comes to health and social care prediction."

As the discussion drew to a close Watts added that there are also benefits data can offer in terms of workforce planning too. "It could help around developing our workforce of the future by helping us understand what are the bulges of demand that are coming in or are likely to create demand on social care in the next 5 to 10 years so that we can start thinking about how to make sure our staff are trained to either reverse the curve around that demand or deal with some of those additional conditions that are not yet so prevalent."

Winding up the conversation, Siggins noted that there was a clear interest in harnessing the potential of data to improve services around the table. "It's very clear that we've all got an interest in early intervention and prevention although with our focus on heavy end demand we may not always have been focusing on predictive modelling relating to prevention but there is a real appetite to do that," she said. "We also cannot assume that everybody is at the same level or stage in their understanding and use of predictive modelling but there is a real push and desire to be focusing at a whole system and to think about the whole system rather than silos that really came out of the discussion today."

From the discussion the opportunities are apparent but, the roundtable's participants noted, there is a need, in this journey towards more effective use of data for health and care, for local areas to share their learning and, importantly, to balance the need to share with the need to keep the information used safe and secure.



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