



# Better Care in the Age of Automation

Data, skills and culture for a sustainable, effective and fair care system

doteveryone

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Visit [www.doteveryone.org.uk](http://www.doteveryone.org.uk) to learn more.

Doteveryone  
West Wing, Somerset House  
WC2R 1LA

+44 (0)20 7257 9397  
[hello@doteveryone.org.uk](mailto:hello@doteveryone.org.uk)  
[@doteveryone](https://twitter.com/doteveryone)

This report was funded by grants from the Tides Foundation and Omidyar Network. A full list of Doteveryone's funders can be found at:  
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Nicholas L, Miller C. (2019) Better Care in the Age of Automation,  
London: Doteveryone. <https://doteveryone.org.uk/report/bettercare>

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# Foreword

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How we care for one another when we are at our most vulnerable is the litmus test of our humanity.

But too often technology and humanity are placed in opposition to one another. At its worst, technology turns people, and all the wonderful messy complexity of their lives, into a mechanised list of jobs to be done as fast and as cheaply as possible.

It doesn't have to be that way. Automation need not preclude empathy. By putting the needs, skills, and relationships of the people who care, and people who rely on care, at the heart of decisions, technology can support all of us to create a better care system.

The failings of our current system are too heartbreakingly apparent. Technology, used responsibly, can be part of a solution. The practical recommendations here show what it would take to make that possible, if we have the courage to imagine a different future.

A handwritten signature in black ink, appearing to read "Martha Lane Fox". The signature is fluid and cursive, with the first name "Martha" written in a larger, more prominent script than the last name "Lane Fox".

**Martha Lane Fox**  
Executive Chair & Founder  
Doteveryone

September 2019

# Executive Summary

## A better care system is possible.

Social care need not be something for individuals to fear and a burden for society to bear. It can be a vital part of improving lives, increasing wellbeing and productivity.

The UK's social care crisis takes place amid unprecedented technological change, transforming the homes and communities of the people who need to be cared for; the jobs of the people who care for them; and the way decisions are made about the entire health and social care ecosystem.

Decision makers must recognise this profound change and - in place of ill-founded tech dreams or ad hoc digital sticking plasters - create a robust care innovation strategy that accounts for it.

This report sets out how technology can support a sustainable, effective and fair social care system. It does not prescribe tech solutions but describes the foundations needed for any technology to be responsibly and effectively deployed, specifically:

- the **data** needed to build and measure technology focused on wellbeing;
- the **skills** required to use tech to care;
- and the **culture** to empower people to adopt and shape technology to their needs.

These recommendations don't require more money to be thrown at an already bankrupt system. Instead they show how to strengthen the care system so that future investments in technologies make meaningful change.

The investment required now is the courage and imagination to see beyond immediate crises and build a social care system fit for the age of automation.

# Doteveryone's recommendations

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## 1 Better data for better care

NHSX should deliver a **new national data strategy for social care** with metrics for the wellbeing and productivity of individuals, families and communities and so incentivise the development of technologies for long term benefits.

## 2 Better skills for better care

The Department of Health and Social Care should support the founding of a **Royal College for Carers** to professionalise the care workforce so they can effectively use technology to augment their vital skills of empathy, creativity and social intelligence.

## 3 Better culture for better care

NHSX should fund vanguard **Enablement Panels** that show what good looks like and get health and care technology working on the ground. Run by and for disabled people, carers and families, these panels will push back against an ageist culture, with favouritism to able bodied people, and use new technologies and services to improve access to the economy and community.



# Introduction

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The UK population is living longer with more long term health conditions. The population who needs support is growing relative to the workforce who can provide that support; leading to worsening funding and staffing crises. Some have pointed to new technologies offering straightforward replacements of human carers through robotics and smart homes as an answer but there is little evidence of these working in practice.

At Doteveryone we champion responsible technology; technology that supports a fair and inclusive, democratic society. Technology can be part of the more profound structural and social change we need to reach a sustainable and fair care system. But rather than reinforcing an artificial divide between able-bodied and disabled people, old and young, technology must be part of breaking down these barriers. It must support more people to access the economy and community in ways that suit them. It must flex around their needs and responsibilities to work, to volunteer, to participate, to connect and to care throughout longer lives.

But the UK care system is in crisis. After years of chronic underinvestment it's been pushed beyond breaking point. Over 1.2 million people don't get the care they need.<sup>1</sup> Care visits of just 15 minutes are becoming the norm, with five minutes increasingly common. A third of

**Technology can be part of the more profound structural and social change we need to reach a sustainable and fair care system.**

councils expect to run out of funds in three years, and a quarter of home care providers are almost bankrupt.<sup>2</sup> Over 110,000 care roles are unfilled,<sup>3</sup> many workers receiving below minimum wage due to unpaid travel time,<sup>4</sup> and the mental and physical health of families who care are in decline. Over 100,000 EU nationals work in social care, and 90% of workers will not meet the £30,000 salary threshold for an international visa. This means Brexit is expected to “worsen the situation.”<sup>5</sup>

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<sup>1</sup> Age UK (2017) 'Briefing: Health and Care of Older People in England 2017'. [https://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/The\\_Health\\_and\\_Care\\_of\\_Older\\_People\\_in\\_England\\_2016.pdf?dtrk=true](https://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/The_Health_and_Care_of_Older_People_in_England_2016.pdf?dtrk=true)

<sup>2</sup> Opus (2017) 'One in four home care companies on the brink of bankruptcy in the UK'. <http://www.opusllp.com/one-four-home-care-companies-brink-bankruptcy-uk/>

<sup>3</sup> Skills for Care (2018) 'The state of the adult social care sector and workforce in England'. <https://www.skillsforcare.org.uk/NMDS-SC-intelligence/Workforce-intelligence/publications/The-state-of-the-adult-social-care-sector-and-workforce-in-England.aspx>

<sup>4</sup> Homecare (2019) 'Majority of home care workers paid less than minimum wage'. <https://www.homecare.co.uk/news/article.cfm/id/1605174/Most-home-care-workers-are-paid-less-than-minimum-wage>

<sup>5</sup> Nuffield Trust (2019) 'Joint letter on no deal brexit'. <https://www.nuffieldtrust.org.uk/files/2019-08/joint-letter-on-no-deal-brexit.pdf>

*A third of councils fear they will run out of funding to provide their statutory services – such as adult social care, protecting children and preventing homelessness, within three years.*

LGA Chairman, Cllr James Jamieson, August 2019<sup>6</sup>

Faced with this overwhelming budgetary and policy challenge, technology can seem like the miracle that's needed. And decision makers are turning to it with enthusiasm.

*Longer-term, [technology] is the only way we're going to bridge the gap between finite resources and the growing demand of an ageing population*

Matt Hancock in foreword to Embracing technology in health and social care from the TaxPayers' Alliance, April 2019

There are promises of potentially vast savings to staff costs through automation. The Institute for Public Policy Research calculates 30% of work done by adult social care staff could be automated, with savings and improvements valued at £6 billion.<sup>7</sup> And the UK Robotics and Autonomous Systems Network claims robots could proactively help with “medicine adherence, nutrition and rehabilitation support, as well as social engagement.”<sup>8</sup>

Whether or not these promises can be fulfilled, there's no question that technology is already having an impact on the UK's social care system and will decisively shape its future.

Do everyone believes technology can be a force for good – used to make life better for more people, more of the time. This work, based on research with people on the front line of care, shows how responsible technology can support a sustainable, effective and fair social care system.

We are grateful to all those who participated for their generous sharing of time and ideas. Details of our methodology are available in the Appendix.



<sup>6</sup> Local Government Association (2019) 'LGA responds to HCLG Committee report on local government finance'. <https://www.local.gov.uk/about/news/lga-responds-hclg-committee-report-local-government-finance>

<sup>7</sup> Institute for Public Policy Research (2018) 'Better Health and Care for all'. "We find that across all of the adult social care workforce, 30 per cent of the work could be automated by adapting currently demonstrated technology. If fully implemented, and assuming output remains consistent, this could lead to productivity improvements valued at £6 billion" <https://www.ippr.org/files/2018-06/better-health-and-care-for-all-june2018.pdf>

<sup>8</sup> UK-RAS Network (2017) 'Robotics in Social Care: A Connected Care EcoSystem for Independent Living'. [https://www.housinglin.org.uk/\\_assets/Resources/Housing/OtherOrganisation/UK\\_RAS\\_robotics-in-care-report.pdf](https://www.housinglin.org.uk/_assets/Resources/Housing/OtherOrganisation/UK_RAS_robotics-in-care-report.pdf)



Through this work we identified three areas that must underpin the responsible use of technology in the social care sector.

## ● **Data**

Although the care system collects vast amounts of data, current metrics focus on costs and processes and not outcomes for the individual, family or community. Building and using technology responsibly requires data that measures what matters to people, reflects the interconnectedness of services, systems, and communities, and promotes decision making for the long term.

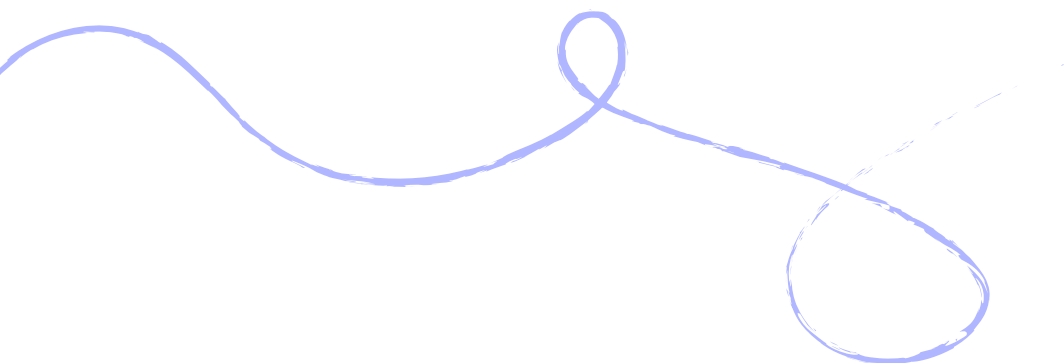
## ● **Skills**

Technology can never replace human care professionals and the complex, relationship-based and creative nature of their work. But used well, technologies can assist in mundane tasks, augment the job of caring and improve people's lives. More technology on the front line will mean more tech support and more complex decision making on the front line and carers will need the skills to do this.

## ● **Culture**

Many benefits claimants are reluctant to adopt new technologies because they fear any change in their lives could jeopardise vital support packages. Older and disabled people feel excluded from an ableist and ageist design community, and complain of unsuitable and unappealing products that don't take into account their own goals, ideas and experiences. Our research participants wanted to "flip the script"; challenging a culture of hostility, suspicion and condescension that prevented them using technology. They wanted to experiment, to share their own ingenuity and ideas in using and adapting technology to their needs and to celebrate ways technology could be part of improved access to the economy and community.

This report describes each of these areas in more detail.



# Better data for better care

How technology is used in social care in the future will be shaped by the data collected on needs and challenges, the targets services need to hit, and metrics by which services are evaluated. Data may be used to train artificial intelligences on how to interact with people or how to predict and prevent problems.

Policymakers, commissioners and staff will then judge the effectiveness of a technology based on the evidence of its impact. How has the service or situations changed over time? Has an individual's health improved or declined? Have their needs escalated? Have national waiting lists lengthened, and have costs risen?

What is measured matters. And better measurements can make a better care system.

## Collecting data

The sector already does a lot of measuring — and those measurements determine much of what happens within the social care system.

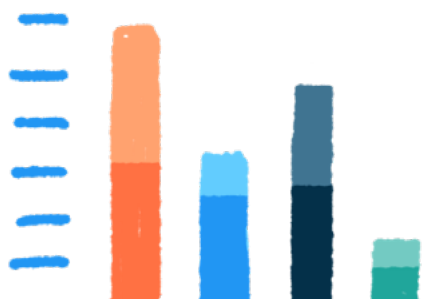
Care professionals and providers told us of the increasing burden and stress of form filling. This uses up precious time that could be spent looking after people. It contributes to low staff morale and burnout. And it also forces carers to do their job to meet the demands of the metrics — which often focus on prescriptive process — as opposed to supporting the overall wellbeing of the person they care for.

Research participants told us of autistic young adults who hate crowds being taken out of the home to sit in a noisy McDonalds so they could tick an “engaging with the community” box. Others told us that in care homes, the fact that a person had been served food was recorded, but not whether or not they had eaten or enjoyed it.

In a system cut to the bone, what's measured is also what's funded. People working at every level of social care, from front line professionals through to managers, founders and CEOs all described pressure to cut back on everything that was not necessary to hit minimum statutory requirements.

*People do wonderful things for the people they care for, they give up far more than their paid time. Responsible providers take on the burden of the cost of additional services - thinking not just about safe care, but about the experience of the person receiving care. But is that fully funded? Absolutely no.*

Executive, major care home operator



## Working with the data

Despite the time and effort spent filling in paperwork, much of the information collected ends up gathering dust, kept on paper in filing cabinets, and referred to infrequently for inspections or review.

*On average [care workers] spend about one and a half hours per shift on paperwork. But it's so complicated to fill in that there's rarely time to evaluate. It's all tracking, with no checking it's actually working.*

Morten Mathiesen, CMO of Digital Care Planning Service, Sekoia

When care providers and innovators do try to use it, they're often disappointed.

*I looked a lot at what different regions and different approaches were achieving and what impact those had on care, but there's nothing - no real data to use. No baseline information. We can only compare against the data we collect when we onboard a client.*

Jonny Bottomley, CEO of Home Care Provider, Edyn Care

Organisations that want to use data successfully have to go above and beyond national requirements, building their own databases, methodologies and training methods. For example Dimensions, a provider of support for adults with learning difficulties and autism, worked with the Tizard Centre at Kent University to develop digital tools and the processes around them. But they had to start from scratch.

*Our Activate model starts with a Possibilities Analysis, using eight 'domains' connected to a good life (health, activities and skills development, and relationships, etc) to help people figure out where they are in their lives and where they want to be. Next we use a systematic, software-based method of goal setting and monitoring to help people take steps towards outcomes that matter to them. Activate is about people not technology; the thoughtful application of great tech enables the meaningful work.*

Nick Barrett, Head of Behaviour Support, Dimensions

The current data landscape also does not serve the needs of those planning and commissioning services. Metrics are analysed in siloes and incentivise short term decisions, failing to account for how changes to one service will affect others.

*Local authorities' data ... is almost never aggregated to provide data about what people want, whether they are getting it, what is working and what the gaps are.*

Workshop participant

## What's missing?

The greatest data challenge in social care is the amount of basic information that is simply missing.

In spite of rhetoric about investment in digitisation, and Secretary of State Matt Hancock's call for the UK to be a "world leader in data driven health care",<sup>9</sup> vital care metrics have been cut in recent years.

Since the Referrals, Assessments and Packages of Care Service was removed in 2014-15, there is now no centrally collected information about the amount of care hours provided across local areas in England. There is also no centrally collected data on waiting times for local authority care, as this was scrapped in 2010, nor is there any enforced maximum waiting time.

There's no way of knowing the total level of funding in local areas in England because the boundaries of health provision and social care provision don't match up. This also makes it impossible to analyse how investment and cuts in one service affect the performance of another. And while information is collected about the overall satisfaction of people who receive local authority care, there's no data on those who are turned away, or the feelings of carers, the wider community and the general public.

These are just some of the gaps. We describe the scale of missing data in more detail in our report, *Better Evidence for Better Care*,<sup>10</sup> which recommends 33 actions to address the issue.

Against this backdrop, commissioners and providers are making critical decisions about the use of technology to support social care, armed with little more than marketing hype or political pressure. With so little information on the wellbeing of communities, there is little incentive for long-term, joined up thinking that can build capacity and reduce future needs.



<sup>9</sup> Sian Bayley (2019) 'Matt Hancock: NHS must be world leader in data driven health care, says Health Secretary'. Evening Standard. 12 June. (<https://www.standard.co.uk/futurelondon/health/health-secretary-matt-hancock-cogx-ai-conference-in-king-s-cross-london-tech-week-nhs-a4165686.html>)

<sup>10</sup> Cory, G. (2019) 'Better Evidence for Better Care', London: Doteveryone. Available at: <https://doteveryone.org.uk/wp-content/uploads/2018/11/Better-Evidence-for-Better-Care-by-Giselle-Cory.pdf>

# Recommendation

## Measure what matters

Better data is needed for a better care system.

That doesn't necessarily mean more data. But it does mean more useful data. This is data that measures what matters - the outcomes for individuals, families and communities and that looks across the whole system over the long term. It also means training and resources to understand and use that data from the front line through to senior management.

This kind of data will help innovators to build technology that works for more people, more of the time and help decision makers plan strategically and know if they are making people's lives better.

Everyone recommends the Department of Health and Social Care supports **a new national data strategy for social care**. This would sit within a new, well funded social care division within NHSX. It should measure the wellbeing and productivity of individuals, families and communities and incentivise the creation and use of technologies for long term benefits. To do this the department should:

- Conduct research to understand individual and community wellbeing to incentivise the market to deliver real, long term value. This will draw on the insights of the ONS, the OECD Well-being and Progress framework,<sup>11</sup> the European Commission's Active Aging Index<sup>12</sup> and the Wellbeing Economy Alliance<sup>13</sup> as well as the experience of the NHS *Health As A Social Movement* projects and other available resources.
- Hold a broad, participatory national conversation about how to define wellbeing and what metrics should be included. This must involve people in all parts of the care system.
- Collaborate with Councils, the Care Quality Commission, and the Office for National Statistics to include new metrics in surveys and evaluations.



<sup>11</sup> OECD, 'Measuring Wellbeing and progress' (2019) <https://www.oecd.org/statistics/measuring-well-being-and-progress.htm>

<sup>12</sup> European commission, 'Active Ageing Index' (2019) <https://composite-indicators.jrc.ec.europa.eu/active-ageing-index/>

<sup>13</sup> Wellbeing Economy Alliance, <https://wellbeingeconomy.org/>

# Better skills for better care



Technology cannot save the care system on its own.

Technology can't work if there isn't a human around to install it, log in, input data for a profile and features, to reset it if it crashes, notice that it's run out of battery, to explain how to use it, or to ensure it fits users' abilities and needs.

*My aunt has a personal alarm that's supposed to mean she can get help in an emergency, but she also has dementia. Her daughter asked "what do you think that does?" She thought for a long while and said "I think I press it when I want a coffee."*

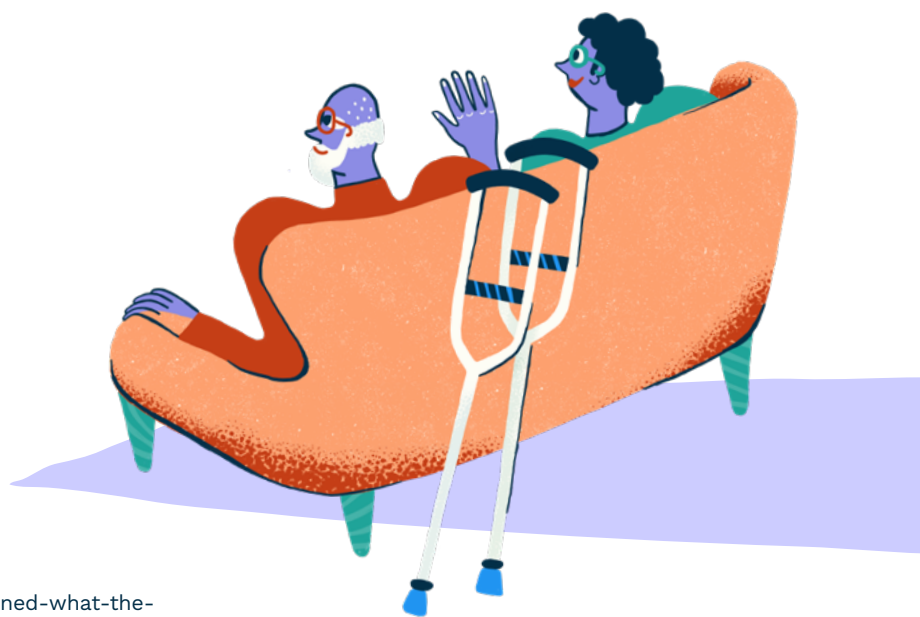
Research participant

Many of the tasks involved in caring are extremely hard for machines: lifting and holding, brushing hair and putting on socks. Emotional intelligence, contextual awareness, creative compassionate problem solving, often under pressure, in messy unpredictable environments are some of the most challenging issues for AI.

As a mixture of "managing others", 'applying expertise' and "unpredictable physical work" social care was rated as one of the least automatable jobs in McKinsey's 2016 report *Where machines could replace humans—and where they can't (yet)*, and again in 2017 as "unpredictable" and so "technically difficult to automate."<sup>14</sup>

Amidst media excitement over care robots, even reviews which discuss the cutting edge in route-finding, grasping, talking and problem solving admit "current assistive technologies are still a far cry from a future where our meals cooked for us and all household our chores are completed for us."<sup>15</sup>

A better care system will depend on having people with the skills to work with technology.



<sup>14</sup> McKinsey & Company (2017) 'Jobs lost, jobs gained: What the future of work will mean for jobs, skills, and wages': <https://www.mckinsey.com/featured-insights/future-of-work/jobs-lost-jobs-gained-what-the-future-of-work-will-mean-for-jobs-skills-and-wages>

<sup>15</sup> Peter Ray Allison (2019) 'Will we ever have robot carers?' BBC. 22 April. <http://www.bbc.com/future/story/20190418-will-we-ever-have-robot-carers>

## Avoiding a widget workforce

Currently care providers are incentivised to use technology to cut staff: there's a global workforce shortage that's set to increase and to become more acute for the UK in particular due to Brexit. Staff make up a high proportion of care costs - typically around 52% of care home costs, rising to 67%<sup>16</sup> if using agency staff. This has led many providers to invest in technologies that get their staff to hit critical targets in as little time as possible, with increasingly detailed and regimented scheduling platforms and tracking systems.

When implemented well, staff management systems can have real value; some front line carers were delighted by a system that let them prove they had turned up to an appointment on time, and helped them to keep track of tasks on a hectic day. But done badly, they give no space for carers to respond with compassion and creativity to the unique challenges of each care appointment; calming someone who's distressed, convincing a deeply confused person that their medication is safe, dressing someone during a flare-up of pain, or washing someone when the hot water on a pre-paid meter has run out.

*They track your position with GPS, when you log in and out of every job by the second - they'll ask why a task took this long today and a different length another day - when it's always contextual.*

Karolina Gerlich, Home care professional & CEO of the National Association of Care & Support Workers (NACAS)

*The tracking means if I pop into the shop on my way to the client to get some milk so she can have tea that's penalised. But it would make such a difference to her day.*

Home care professional research participant

This “widgetisation” of the workforce — slicing the job of caring into prescribed tasks and not seeing the whole picture of a person's needs — has drawn parallels with other safety critical industries, including aeronautic engineering:<sup>17</sup>

*As Boeing rushed to get the aircraft done, many of the employees described a compartmentalised approach, each focusing on a small part of the plane. The process left them without a complete view of a critical and ultimately dangerous system.<sup>18</sup>*

Taken to the point of absurdity in this way, technology doesn't serve the interests of either the staff or the people they are caring for.

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<sup>16</sup> NatWest (2017) 'Care Home Benchmarking Report 2016/17'. [http://www.rcpa.org.uk/wp-content/uploads/2016/12/NAT00339\\_Healthcare\\_Report\\_Midres.pdf](http://www.rcpa.org.uk/wp-content/uploads/2016/12/NAT00339_Healthcare_Report_Midres.pdf)

<sup>17</sup> “The panacea of a “widget workforce” - worker who can fill any gap, in an increasingly high-risk, high-expectation, complex safety critical field is an illusion if good outcomes such as admission avoidance are key” Alison Leary Professor of Healthcare and Workforce Modelling at London South Bank University and The University of South Eastern Norway, <https://reform.uk/the-reformer/staffing-nhs-why-we-need-invest-community-workforce>

<sup>18</sup> Nicas, J., Kitroeff, N., Gelles, D., Glanz, J. (2019) 'Fatal flaw in Boeing 737 Max traceable to one key late decision'. The Irish Times. 2 June, <https://www.irishtimes.com/business/manufacturing/fatal-flaw-in-boeing-737-max-traceable-to-one-key-late-decision-1.3912491>

## What technology and people can do together

Technology does have the potential to reduce costs and improve care if people have the skills and autonomy to make it work. Our research participants told us about smart homes that let them open doors and windows and move around their home safely as their mobility declined, allowing them to stay at home independently. Others said technology had given them access to services and work opportunities.

For some organisations technology has improved efficiency and transparency, or helped them support their workforce more effectively. In many cases platforms and devices have helped people connect and support one another. But achieving these results, scaling and improving on them relies on people being able to get tech to fit into complex, busy lives, to know if something's gone wrong and fix it when it breaks.

Technology does have the potential to reduce costs and improve care if people have the skills and autonomy to make it work.

## The “Last Ten Centimetres”

The logistics industry is familiar with the “last mile problem”. Optimised supply chains are increasingly efficient at moving goods from factory to port to shipping container to lorry to national distribution hub to local warehouse. But the last part — navigating unfamiliar narrow streets to find an address and get a box into customers’ hands — remains unpredictable and challenging, and makes up about a third of the total cost of delivery.

The health and social care system is becoming more tightly controlled, digitised, automated, and tracked. And it’s struggling with the last “ten centimetres”.

The “Last Ten Centimetres” — an idea conceived by our workshop participants — are often invisible to people who do not have lived experience of illness, disability or caring. To an able-bodied designer, getting Alexas in dozens of disabled peoples’ homes so they can use voice controls to set up reminders, switch on lights and open doors may seem like a finished job. But this doesn’t take into account users with conditions that affect their lungs and cannot raise their voice above a whisper. Nor does it consider people who’ve suffered a stroke or who have learning disabilities, and who may not be able to formulate questions in ways the AI understands. Users with dementia are often deeply distressed by an unfamiliar robotic voice reminding them to take medication, and people who come to rely on a smart home system for access and communication can be left in danger if a power cut, hack or missed payment interrupts the service.



*The physical tics make it hard to hold things or press buttons but my vocal tics affect voice recognition. A computer scientist volunteered to work on it - I now have my own custom system that knows the difference between a tic and a command. It's so useful, but it only works for me.*

Jess Thom, theatre-maker and co-founder of Touretteshero

This “Last Ten Centimetres” is critical for both NHS and social care to realise the benefits of new technologies. If telecare appointments are to save GPs’ time, someone needs to set up the WiFi and make sure it’s working. If reminder SMS messages are to improve NHS appointment attendance, someone needs to make sure they are readable or that text-to-speech works. If robot-supported physiotherapy is to improve stroke rehab, someone needs to make sure the straps and grips are comfortable for different hands all affected by hugely varied pain, palsy or paralysis.

*I've been given, I think, four commodes? No five. All with more features but none of them fit me. They won't take the old ones away [...] so my tiny flat is just full of all these useless things.*

Research participant

Crossing the “Last Ten Centimetres” requires combining the non-automatable skills of care professionals - emotional intelligence and empathy, contextual awareness and creativity - with basic technical skills. It also requires giving carers the time and resources to feed back their experiences into tech development, to be able to personalise technology, and to access technical support when things go wrong.

## **2025: A Future of Care**

In our workshops we imagined a positive future, with empowered, trained staff who had the time and resources to listen to the people they support and work with them to identify problems and proactively find solutions. These ideas are explored in **2025: A Future of Care**, a short film we developed with Superflux.<sup>19</sup>

In the film Pam, who has had a stroke, has a smart door system installed to keep her safe and help her manage visits from care workers and friends. When the system breaks down, a trained care professional and a local tech supporter - who has developed skills through managing her own assistive technology - work together to help Pam battle through bureaucracy and system resets. They solve the problem, develop their skills and form a friendship, so end up better equipped to tackle whatever problems come next.

<sup>19</sup> Superflux (2019) ‘2025: A Future of Care’. London: Doteveryone. Available at: <https://youtu.be/UpJtxQ7Rhys>

## The autonomy to care

But as well as skills, an innovative, tech-supported care sector depends on staff having the capacity and autonomy to act.

There is increasing evidence that this approach is cost-effective. In the Buurtzorg model,<sup>20</sup> commonly used in the Netherlands, small self-managing teams of highly trained community nurses provide all of an individual's care (rather than separately managing personal care, nursing care or advice).

Although skilled staff cost more per hour, given autonomy and resources, nursing teams quickly identify barriers and efficiencies, and so reduce overall care hours required. Since the introduction of this approach costs have reduced by around 40%, the time taken to administer care has fallen by 50%, and while those supported receive fewer care hours they and their families report higher satisfaction with the service.<sup>21</sup>

In the UK this flat, self-organised model is being trialled in some district nursing groups and by Wellbeing Teams, a provider that organises care professionals into community circles. This approach has already allowed them to use technology effectively:

*We take an asset based approach and try to understand each person and their context. We ask them how they're doing now, what their hopes are for the future, then what have you already tried and what worked. Then we can proactively help them with self care. This is digital first; if there's an off the shelf tool we go with that; VR for pain, calendars, CBT apps, wearables. It depends on each person's situation and needs.*

Helen Sanderson, Founder and CEO, Wellbeing Teams

Empowering staff to be creative in this way will be vital to the successful adoption of technology that supports people's wellbeing.

<sup>20</sup> Buurtzorg, <https://www.buurtzorg.com/about-us/buurtzorgmodel/>

<sup>21</sup> Royal College of Nursing, The Buurtzorg Nederland model, (2016), <https://www.rcn.org.uk/-/media/royal-college-of-nursing/documents/policies-and-briefings/uk-wide/policies/2015/br-0215.pdf>



# Recommendation

## Invest in skills

Technologies in health and care will not deliver efficiency gains, cost savings, or improvements to people's lives without the capacity or skills on the frontline to implement and support them.

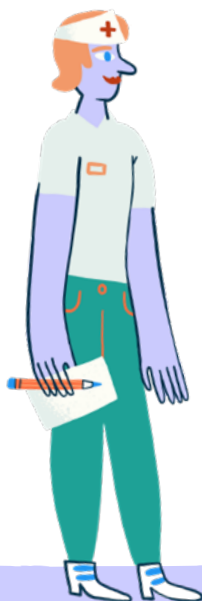
Care professionals who are expert in contextual, creative problem solving, emotional intelligence, and negotiation of sensitive topics and physical pain can cross the "Last Ten Centimetres" of tech if they're given the skills and autonomy to do so. They may not perform every fix themselves, but they can flag up problems and coordinate support.

More well trained and supported staff will mean greater productivity, less spend on agency staff, lower turnover, higher quality care, and more capacity to use new technologies effectively.

Everyone recommends the Department for Health and Social Care should establish a **Royal College for Carers** to professionalise the care workforce so they can effectively use technology to augment their vital skills of empathy, creativity and social intelligence.

The college will require funding, and more qualified staff will mean higher pay. But this approach will save money over the long term for both individual providers and the wider health and care sector. More well trained and supported staff will mean greater productivity, less spend on agency staff, lower turnover, higher quality care, and more capacity to use new technologies effectively. The college should:

- Offer flexible, distance and online cohort learning for carers that develops technical skills in tandem with existing emotional intelligence and problem solving skills.
- Make resources available to related professions, informal carers, and individuals practising self-care.



# Better culture for better care

Together, better data and better skills could make great technology that aims to meet the needs of social care. But technology will do no good unless the people it's meant to help feel able to take advantage of it and make it work for them.

The culture a technology lands into can determine how effective it will be.

Technologists pride themselves on disruption. But to vulnerable people, disruption — in fact any change at all — can be frightening, even life threatening.

People must feel empowered to engage with and shape how technology is used within a sustainable social care system.

## Unblocking the opportunities

A 2016 inquiry by the UN Committee on the Rights of Disabled Persons (CRPD) found disabled people in the UK were consistently portrayed as “dependent or making a living out of benefits, committing fraud as benefit claimants, being lazy or putting a burden on taxpayers” and that they suffered “grave and systematic violations” of their human rights<sup>22</sup>.

Many of our research participants had their own experience of this. They told us that benefits assessors were always looking for an excuse to cut funding; that trying to recover, to adapt or to learn new skills would cause vital support services to be taken away; that any temporary change in circumstance could be used as justification to take away long term support.

*I used to volunteer in a charity shop a few days a week. They understood if I was too ill to come in or if I was dizzy and needed to sit down or had to leave early or if I forgot things. But the DWP [Department of Work and Pensions] found out and then cut all my benefits and said I should be working full time in a shop. I can't work full time! I tried but I couldn't even do the interview! It took months to get my support back and I needed to borrow money for food. I will never dare volunteer again.*

Research participant

This fear inhibits the potential for people to take up new opportunities - and means people justifiably fear engaging with tech and services that could mean their situation is seen to have changed.



<sup>22</sup> UN Committee on the Rights of Persons with Disabilities, Inquiry concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee under article 6 of the Optional Protocol to the Convention, (6 October 2016). Available at <http://www.ohchr.org/Documents/HRBodies/CRPD/CRPD.C.15.R.2.Rev1-ENG.doc>

The social care system is built around a culture of ageism and ableism: people are either ill or well; supporting or being supported; completely dependent or working full time; old and frail or young and vigorous. But the reality is a lot more complicated.

*Many of our workers were made redundant or squeezed out of work while very much still able and willing to work - others can't work full time any more but need or want to still work. Flexibility is key. They can work one Tuesday, have a hospital appointment the next.*

Research participant

Our participants all had stories of fear and distrust, but they also had ideas of the future they wanted to live in.

They imagined “flipping the script” on assessments; developing support panels where they would meet groups of experts — including people like them — who could share ideas and solutions, technologies and services that could help improve wellbeing, are centred on personal goals and build upon a person’s existing skills, relationships and strengths.

## Untapped ingenuity

Living with a disability or a chronic condition is hard work. The world has been designed for able-bodied people. Adapting it to people with different needs takes a lot of energy and time. But it also develops ingenuity, and provides a different perspective on the world.

Disabled and chronically ill people, their carers and families have many ideas and solutions for overcoming everyday challenges and — as technologies become part of their lives — for making tech work for them.

But they have little opportunity to share the helpful hacks and workarounds they develop. On a number of occasions, people in our research workshops mentioned a problem they faced with technology — an app or a device that would be incredibly useful if only it worked — and someone in the room had already found a solution.

*Every disabled person becomes an engineer of the technology and equipment they use.*

Matilda Ibini, playwright & screen writer

**On a number of occasions, people in our research workshops mentioned a problem they faced with technology ... and someone in the room had already found a solution.**

Sharing this information shouldn't be a question of serendipity. To get tech working well for people, it's vital that people can systematically share and have access to relevant expertise. This could help more people get greater benefit from the technologies they have access to; it could inform future care technologies; and also help create a more vibrant innovation landscape. A movement of patient-led research and design in healthcare over recent decades has resulted in new understanding, new drugs and revolutionary devices such as the artificial pancreas, designed by and for people with type 1 diabetes and their families. In the US the

The Disabled List,<sup>23</sup> a group of creative disabled people offer design consultancy.

User-centred, iterative design is now the de facto standard for digital products and services across UK public services, including those created by NHS Digital. However, the same scrutiny and person-oriented thinking is not applied to how internet-connected devices and other technologies are deployed within the home. The next wave of technological development should not and cannot be led by industry or the NHS alone. Based on the maxim “Nothing about us without us”, disabled and chronically ill people should be given the voice and the resources to make sure technology works for them.

## Recommendation

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### Empower the people that matter most

If technologies are to support people to live well, people must be empowered to adopt, use and improve them.

Changing a welfare system in which suspicion, hostility and fear have become ingrained requires broad societal shifts that are beyond the scope of this project, but at Doteveryone we believe it is possible to provoke change by imagining alternative futures and showing what good looks like.

We recommend that NHSX, with advice from a consortium of self-advocacy groups, fund a series of **enablement panels**.

This proposal reflects the ideas and hopes of our workshop participants as well as the critical need for a culture change so that more people can benefit from health and care technologies.

Rather than focussing on deficits, these panels would concentrate on the capacities and goals of the person being supported, their family, their community, and their support team. Over the course of several months, the enablement panels should listen, reflect, and explore how new technologies and services can help people achieve their goals and improve access to community and the economy.

- These panels will need to be optional and to be carefully separated from benefits assessments, so that building confidence and capacity is not punished by cuts to support in the short term.
- The project should include a training and support scheme that builds a cohort of disabled, ill, older and caring designers.
- Using an asset-based and goal-oriented approach, panels should seek to support users over a period of months to explore how tech can help them achieve their own ambitions, with resources for staff, family and community.

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<sup>23</sup> <https://www.disabledlist.org/>

# Conclusions and next steps

The 2020 Spending Review has brought good news for local governments and social care; financial investment is welcome and timely, but it is not enough.

To meet the challenges of the coming decades, social care must shift its ambitions from keeping people alive to supporting them to thrive. Short-term funding is useful, but the whole sector — including social care leaders, carers, and disabled and critically ill people — must have the latitude to escape survival mode and the opportunity to come together to create better, more equitable, enjoyable and sustainable futures. Making this work requires strategic thinking and hard work, not just optimism and a will to innovate.

As this report shows, technology can help to solve parts of the social care puzzle, but it cannot perform magic. Using technology unwisely will make things worse; this is not a short-term innovation project, but a long-term investment in better data, more relevant skills, and empowered communities.

Overall life expectancy in the UK is getting longer, but healthy life expectancy is getting shorter<sup>24</sup>. The working population and the care workforce are both shrinking, while the population of sick and disabled people is growing. Today's failing system is not sufficient to serve the people who will need care tomorrow, let alone in 10 or 20 years' time. A skilled, caring society in which every member is supported to participate in the community and economy is the answer.

There exists an enormous opportunity to make the most of the skills of older and disabled workers and carers, to improve working conditions and staff shortages in the care sector, and for a lively, diverse innovation landscape that enhances the UK's competitiveness in a changing world. While finance is a challenge, the key problems are cultural and structural and are open to change.

The debate over the future of social care has been mired for decades. In that time, new technologies have created new facts on the ground. The current political impetus to address the crisis in social care is welcome, but no 'fix' will succeed unless it recognises the reality of delivering care in a digital society.

This report clearly identifies the necessary conditions for social care in the age of automation: better data, better skills and a better culture. We urge decision makers at every level to recognise these as the essential foundations for the future of social care and build on them to create a sustainable, effective and fair system.

**The current political impetus to address the crisis in social care is welcome, but no 'fix' will succeed unless it recognises the reality of delivering care in a digital society.**

<sup>24</sup> The Health Foundation (2018) 'The healthy life expectancy gap'. <https://www.health.org.uk/blogs/the-healthy-life-expectancy-gap>

# Appendix

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## Methodology

The Better Care Systems project started by speaking to people on the front line — people who receive care and support, their families and carers, care professionals and clinicians.

From those stories we drew out themes and challenges as frames for interviews with a broader range of experts: academics, technologists, associations, policymakers, start-ups, co-ops and charities.

We commissioned leading data scientist, Giselle Cory, to find natural experiments that might substantiate some of the recurring themes. Cory concluded that data in the sector was so poor that such analysis was impossible. Instead we set out in *Better Evidence for Better Care*,<sup>25</sup> the necessary groundwork for this analysis. The report provides; an overview of the social care sector's data, its limitations and the implications this has for decision and policy making in social care.

The core of the work was three futures oriented workshops in London and Birmingham. Participants explored cutting edge case studies and debated how those technologies and policies might affect their own lives and projects, including the potential unintended consequences. Then, with structured exercises, they developed visions of a sustainable, fair care future. And using these visions, together we explored what policies, products, campaigns and developments would be needed to get from our current care system to this imagined ideal.

The workshop methodology drew on horizon scanning and the futures wheel, described in the Government Office of Science Futures toolkit,<sup>26</sup> and adapted following advice from organisations which support people with learning disabilities in order to be accessible. For many this was the first time they had been asked what they wanted from their care, or from their jobs and gave participants a chance to look up from the crises they face every day, and think ambitiously and optimistically about what would work for them in the long term.

*Thank you so much for inviting me. It really inspired me to feel more excited by health and care and to encourage change which had been a struggle for a while.*

Specialist Dementia Nurse & research participant

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<sup>25</sup> Cory, G. (2019) 'Better Evidence for Better Care', London: Doteveryone. Available at: <https://doteveryone.org.uk/wp-content/uploads/2018/11/Better-Evidence-for-Better-Care-by-Giselle-Cory.pdf>

<sup>26</sup> Cabinet Office and Government Office for Science (2014) 'Futures toolkit for policy-makers and analysts'. <https://www.gov.uk/government/publications/futures-toolkit-for-policy-makers-and-analysts>



In order for our research to be representative and to reach past the usual suspects and loudest voices we needed the workshops to be widely accessible. We describe thus processing more detail in our blog post: *How to Design Accessible and Inclusive Workshops*.<sup>27</sup>

We also travelled to support groups and providers in Bristol, Brighton, Manchester, Hebden Bridge and Congleton, to get varied perspectives from different regions, towns, villages and rural environment, and from families for whom travel was impossible.

The insights from interviews, workshops, site visits and data analysis all contribute to what we hope is a holistic, respectful portrait of the sector, and reflects the ideas and expertise of our generous participants who rely on it, work in it, study it and campaign to reform it.

## Films

Critical decisions on the social care sector are made at every level of what is a complex fragmented sector - from Commissioners and CEOs, through IT and learning and development teams, technologists and designers, researchers and investors to the frontline support staff, carers and people who receive services. There is no clear hierarchy of decision-making and strategy definition. Therefore, for our reflections and recommendations to gain traction they needed to travel beyond the council chamber and the board room.

So alongside this report, we developed two short films which we hope can be watched and discussed during the varied, busy schedules of people who provide, receive, research and work in care.

The first, **2025: a Future of Care**<sup>28</sup> was developed by award-winning design studio, Superflux, and builds upon the ideas and stories of our workshop participants. The film features Pam, a woman who has suffered a stroke in her 60s, Nadia, a care professional in her late 50s, and Yanni, a younger tech support worker with a physical disability. They use a variety of new technologies - driverless cars and medication reminders, telepresence robots and voice activated smart homes - to come up with creative solutions to practical and bureaucratic challenges. Their world isn't perfect and resources aren't limitless, but it shows how, with support to retrain and to access work and with longer flexible care visits, everyone's skills and ingenuity can be part of the solution, and trust and friendships can form. All of our performers had personal experience of receiving social care services, providing unpaid care or working in the care sector.

Our second film **Better Care Systems**,<sup>29</sup> produced by Dragonlight Films, summarises the evidence and arguments of this report. In particular, it underlines the value and complexity of care work, the growing workforce shortage and the importance of working with frontline staff, people who receive services, their families and communities, on developing solutions.

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<sup>27</sup> Nicholas, L. (2019) 'Imagining Better Care Systems - how to design accessible and inclusive workshops'. Available at: <https://doteveryone.org.uk/2019/02/imagining-better-care-systems%E2%80%8A-%E2%80%8Ahow-to-design-accessible-and-inclusive-workshops/>

<sup>28</sup> <https://youtu.be/UpJtxQ7Rhys>

<sup>29</sup> [https://youtu.be/jN\\_r3j1JBDA](https://youtu.be/jN_r3j1JBDA)

# Acknowledgements

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We are profoundly grateful to all those who contributed to our research through participating in workshops and interviews, and by granting us a window into their networks and organisations through site visits, workshops, meetings, and events.

Funding for this research was provided through grants from Tides Foundation and Omidyar Network. Independence is vital for Doteveryone to be able to carry out our mission and funders do not influence Doteveryone's priorities or policy positions.

This research was led by Lydia Nicholas. The report was written by Lydia Nicholas and Catherine Miller, and designed by James Barclay. Illustrations are by Elin Matilda Anderson.

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Doteveryone  
West Wing, Somerset House  
WC2R 1LA

+44 (0)20 7257 9397  
[hello@doteveryone.org.uk](mailto:hello@doteveryone.org.uk)  
[@doteveryone](https://www.doteveryone.org)

[doteveryone.org.uk](https://www.doteveryone.org.uk)

