

# Care Software Providers Association



2020/2021 Virtual Roundtable Series

***Maximising how software & systems  
can improve the quality of care...***

***Who should see what information?***

**Session Two, 3<sup>rd</sup> December 2020**

## ROUNDTABLE NOTES

## Contents

	Page
The Care Software Providers Association (CASPA)	1
Roundtable Executive Summary	2
Roundtable Introduction	4
Part 1: <i>Who should see what information?</i>	5
Part 2: <i>How do we bring alignment of controllership and the individual deciding who can see their data at any given time?</i>	7
Part 3: <i>How can the Regulator and others help to encourage data sharing?</i>	
Reflections and next steps	11

**The Care Software Providers Association (CASPA)**, is an independent association representing the views and interests of social care software providers across the U.K.

The objectives of CASPA are:

1. The promotion and continued growth of the use of digital technologies in the social care sector to improve the quality of care delivered
2. Promoting advances in the digital information flow across social care to provide openness and transparency of care being provided
3. Lobbying parties outside social care to improve the digital information flow between social care and others, in particular the NHS
4. Creating standards, such as those for electronic information transfer, where such standards do not currently exist
5. To create a framework to assist in providing service continuity for members customers

[www.caspa.care](http://www.caspa.care)

## Executive Summary – key conclusions from the Roundtable

- o Data saves lives
- o Data sits with the individual and they should decide who to share it with
- o Data sharing can significantly affect how people receive care and improve the quality of that care
  
- o The regulator has a significant role to play in helping the acceleration of the uptake of digital care. There is a willingness to work in partnership with all stakeholders to help to drive the joining up of care between health and social care
  
- o The appropriate people in social care must have access to data in a timely manner and this must be applied to those who need to see data as part of the care process (e.g. registered managers). The lack of clarity over who can see care records needs to be raised at the highest levels
  
- o The regulator wants to get a better view of quality and plans to review the assessment framework
  
- o There is a need for a Vision of the Future for data sharing in social care and health over the next five years and what this could look like. As leaders in social care, the groups represented at this Roundtable were keen to work with CASPA to produce a joint document which would help to drive national policy.

## Roundtable Introduction

This virtual roundtable event, the second in a series to be continued through 2021, was established to bring leaders from across the UK social care sector together; namely care providers, care representative organisations, technology suppliers and those from technical departments within the NHS, with the high-level aim of maximising how software and systems can improve the quality of care.

The second event included care companies delivering residential or domiciliary care, the industry regulator, care software providers, and independent social care associations representing home care, independent residential care and not-for-profit organisations in the care and support sector as well as representatives from digital and technology divisions of the NHS.

The roundtable was held under **the Chatham House Rule**. As such participants are free to use the information received and best efforts have been made in the preparation of this write up to avoid revealing the identity, or the affiliation of the speaker or revealing the identity of any participant.

The term **digital** is used by speakers in reference to both the specific use of digital care management systems as opposed to paper based social care records, as well as being used in the broader sense to describe the shift to a more technology enabled social care system, for example using internet of things (IoT) devices to remotely monitor care receiver activity, safety or health.

## ***Part One: Who should see what information?***

Each participant briefly outlined their views around the topic of who should see what information and the impact that data access can have on care quality in social care.

- Access to data saves lives and we need to get ourselves to a place where health and social care data can be shared effectively
- Often there are instances where people cannot access vital data and information – this can lead to tragic consequences
- Exciting potential for sharing data could significantly affect how people receive care – care information being recognised by care professionals for the benefit and improved well-being of the individual
- Not just technical barriers determine who can access information, but also culture and language plays an important part
- Lack of coding systems between health and social care is a barrier to the better use of data
- The move in the narrative is a positive one: everybody now understands the benefits of being able to access information and now we need to address the challenges and barriers which prevent those who need to access to data, such as registered managers
- The person whose data it is, should decide who to share it with. Data ownership rests with the individual and they must approve the sharing of their data. The NHS accepts that this is a barrier because the general public needs to gain confidence in sharing data at a national level
- Much has been done at a local level, but this needs to be placed on a national stage and the challenge is that the industry and the NHS are not making enough noise about the successes that sharing data makes in saving lives and improving the quality of care
- Social care has been seen as a second-class citizen for too long and this is now changing, especially due to the NHS social care programme and organisations like CASPA, which demonstrate and promote the rich value of the data which is available from digital systems within social care

- NHS D has developed 5 standards for data sharing. It has been recently agreed that social care can access the Summary Care Record (SCR), which covers 91% of the population
- There is a need to join up services. For example, South Gloucestershire has care homes sharing data with health care, whilst Sutton is using the National Records Locator (NRL) for country-wide connections for the eRedBag
- There needs to be clarity on who can see care records
- The NHS Digital social care programme is due to end in March 2021, and at the moment there is nothing planned to replace it. Therefore, NHSX will hold responsibility for taking this area forward, and there is need for this to be highlighted in order that all the good progress that has been made in digital social care is not lost. Organisations, like CASPA, have an important role to play in developing collaborative partnerships between NHSX and the care community. Building blocks for sharing data between health and social care are in place, but it may be up to 10 years until people are ready for total adoption
- The safety aspect of who can access data is of paramount importance
- Information at discharge is especially poor. Example of lack of available data: paramedics returned man to his home after discharge from hospital, unaware that his wife was too frail to care for him. Consequently, he was left in a wheelchair in the hall all night suffering from incontinence until care workers arrived the following day. There is a real need for the Government to do more to ensure that the right people can access information and that this is made readily available to them at the point of care delivery
- Nursing home and hospital staff use different systems which do not share data, and this necessitates clinical governance meetings to discuss who had submitted what data onto which system
- Agreed that care homes have a much deeper level of data for sharing, but a major barrier is inputting this into relevant systems. Would be much more simple to enter data once and then share, as already happens in many social care record systems
- The quality of care and quality of life are closely linked
- Joined up care improves the quality of life: “if we cannot join up the information, then we cannot join up the quality of life”



- Regulator recognises that it is important to share what we have by providing access to those who need it
- Regulator also recognises that everybody is not working to the same definition of quality, nor to the granular level which we need to achieve – this is the major challenge
- In the next 12 months, the regulator will be reviewing the assessment framework with the objective of getting a better view of quality
- Need to work at breaking down interoperability challenges, including where staff move between different settings and the transient nature of their jobs often means that carers have multiple employers and move around the system a lot
- There needs to be sharing of data between residential and domiciliary (as well as between health and social care)
- New care models are often limited by the lack of data sharing and this holds back the benefits of digital systems – e.g. (i) in reviewing a risk or a treatment a GP can save at least 30 to 60 mins by just knowing what social care has been provided; (ii) home care agencies would benefit from knowing medications, allergies, major medical conditions
- Commercial viability of digital solutions is a problem, particularly for domiciliary care agencies – e.g. cost of connection
- One route for data sharing (SCR) was discussed in some detail, whilst others such as GP Connect and LHCRE's also exist.

Summary Care Record: only available for GP to view

- Basic record: allergies, medications and adverse reactions
- View only record
- Original take-up only 3m records. Now up to 55m records with the increased functionality of additional information providing a more rounded summary
- SCR should continue to be rolled out
- SCR would benefit from inclusion of the “About Me” information
- No clarity on who can see SCR. In pilot at Uplands home, only registered clinicians (GPs) can access SCR, which is hopeless because care home managers and carers need access in order to deliver quality care. This lack of clarity over who can access records needs to be raised at the highest levels
- Interoperability crucial – enabling data to be seen by many more widely

- o e.g. ambulance crews ask for prescriptions when collecting a person; could then call up SCR and compare with the paper prescription
- o Also large benefit if the home care agency could see the SCR as well
- o Sutton project: drawing pieces of the jigsaw together: linking across all parts of the care spectrum
- The data sits with the individual.

***Part 2: How do we bring alignment of controllership and the individual deciding who can see their data at any given time?***

- Numerous discussions with NHSD over time about opt in or opt out
  - o Must not permit a rigid set of permissions which in turn create barriers, preventing someone who needs to see data from accessing it
  - o COVID has shown that *“the assumed ways of working”* can be changed and this momentum must not be lost
- The Regulator currently has two roles:
  - o Health framework and Adult Social Care
- But there needs to be a single role which more clearly reflects greater collaboration and puts the person at the centre. Regulator keen to move the debate forward and possibly technology may have to catch up
- There are complications around personal data – explicit consent and implied consent. In social care there are no IG officers (as there are in health) and also social care has to work from imperfect guidance. There is not any professional guidance or central voice.
- The advice of the National Data Guardian (Caldecott) needs to be more clearly directed, acknowledging that there is a difference between health and social care
- Discharges from acute settings are an issue, especially for domiciliary care providers
  - o Discharges get pressurised particularly on a Friday
  - o Discharges often poor with post-it notes placed on stretchers
  - o Limited information available, if any

- Whilst 30% using digital care systems, there is a need to get all providers off first base by providing basic infrastructure and this needs lobbying for

### ***Part Three: How can the Regulator and others help to encourage data sharing?***

- In the short-term, the Royal Colleges need to get involved, and we should press for this as a sector, and the regulator could help to facilitate these conversations
- In the longer-term, we need to know what people expect and “think local and act personal”. Focus on the “I” questions, such as “I am able to choose who sees my information” and make these the regulatory basis of assessment for quality
- In the medium-term, data sharing can greatly improve how regulation works and how social care evolves – e.g. GP records shared with care providers. The regulator could help to make this happen by defining what the vision is for digital adoption and the benefits that this would bring for those in care, the carers, the caregivers and the regulators. Such an approach would be a win/win for both NHSX, the regulator and social care
- Opportunity for this group to set the vision and ambition for the sector – everybody is waiting for NHSX to set the agenda. Perhaps the time has come for those in this group and others to set the agenda and help to influence the uptake of digital systems and the sharing of personal data by those who need to see it
- This group should “specify what is the data that is required; who are the people that need to see it; and so this is what should happen...”
- Working with the regulator CASPA could co-author a vision of data sharing in 5 years’ time – the group agreed that this would be a good initiative, and this was supported by all attendees

## **Reflections and next steps from the roundtable discussion**

Throughout the roundtable, it was clear that social care is currently undergoing a structural change for the better, as digital tools and technology transition from being used successfully by a minority of organisations, to becoming business as usual for social care providers, the regulator and local authorities. While this direction of travel was unanimously accepted by all groups participating, several enablers and barriers to widespread digital use were identified and reviewed.

As leaders in social care, this group agreed that it could wait for direction from the centre or that it could be proactive and start to direct the narrative.

Appropriate access to data is key to all aspects of successful digital uptake and the significant benefits that this brings. The participants supported the production of a jointly authored vision document outlining what data sharing could look like in five years' time.

CASPA will coordinate the production of this vision document.

Participants agreed to continue this discussion at the next roundtable, scheduled for the first quarter of 2021.

*CASPA has been established in the UK as an independent, not for profit, member-driven association. Membership is available to companies involved in the provision of software to the care sector. The association is currently led by a volunteer group of founding board members, each of whom manages a well-established software company that provides solutions for social care providers.*

*For further information regarding membership and CASPA activities, please contact [membership@caspa.care](mailto:membership@caspa.care)*

© 2020 CASPA All rights reserved