Guide To
SUPPORTING CARERS
THROUGH TECHNOLOGY ENABLED CARE SERVICES
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Introduction

by Grainne Siggins, Joint Chair, ADASS Carers Policy Network

ADASS has a long-held commitment to supporting carers and contributing to the development of support and services which enhance the quality of life of carers. The ADASS Carers Policy Network has worked consistently with a wide range of partners in undertaking this role and this latest report continues that tradition. The subject of this report concerns technology enabled care services and the way they can support carers.

The origin of this report came out of a lively workshop with members of the Association of Directors of Adult Social Services (ADASS) Carers Policy Network in November 2014. Following presentations and discussions facilitated by Tunstall Healthcare and Carers UK, there was an overwhelming consensus that technology enabled care such as telecare, can be an enormous help to carers but awareness of what was available and how to get it was limited. Therefore, it was agreed that a report should be prepared and that its target audience should be commissioners in care and health and other organisations.

This report comes at an important point in time. With the implementation of the Care Act earlier this year and the strengthening of the rights of carers, it is essential that local authorities, health services and other organisations review the way in which they can improve the support carers receive. There is considerable evidence to support the view that technology enabled care services can improve the quality of life of carers and therefore it is important that commissioners understand the range of services that are available and the ways they can support carers. Technology is woven throughout the statutory guidance in the Act, particularly in the areas of information and advice, integration and prevention, providing a big opportunity for using technology to support carers and the people they care for.

By highlighting the role that technology enabled care services can play in supporting carers, it is hoped that the target group of this publication – commissioners in care, health and other organisations – will become more aware of the opportunities and more capable of commissioning such support effectively.

What is clear from this report is that technology enabled care services can offer reassurance to families and reduce the pressure they come under in a wide variety of ways. From offering peace of mind to emergency responses, technology enabled care services can provide personalised responses to complex challenges as part of an overall package of care and support.

ADASS Carers Policy Network will continue to promote good practice in supporting carers and sees this report as part of that ongoing support. It provides a valuable guide to commissioners and I hope that through it, carers across the country will benefit even more from technology enabled care services.

Grainne Siggins
1. Executive Summary

**Technology supports carers**

The benefit to carers from technology enabled care and support is considerable as identified in a survey with carers carried out in 2012 – the first of its kind ever undertaken in relation to telecare and telehealth:

- Over 60% of carers surveyed said telecare/telehealth had given them peace of mind as a carer.
- One in eight carers said telecare/telehealth had helped them stay in work or return to work alongside caring.
- Almost two thirds of carers not using telecare/telehealth were unaware of the support available from technology.
- Of carers not currently using telecare/telehealth, one in four would like it but simply did not know where to find it.¹

There are also other ways in which technology related care and support services can provide additional support to carers.

When asked about telecare, in a Carers UK/YouGov poll, there was very low awareness of telecare technology, with only 12% of the population saying that they would use it. When the term was explained to them, 79% of people said they would use it and this was even higher for the over 85s.²

¹ & ² Carers and Telecare, 2012, published by Carers UK
2. What do carers need?

A workshop was held with the ADASS Carers Policy Network looking at technology enabled care and support services, everything from telecare/telehealth and carers apps.

Here’s some feedback from the workshop about what carers told us:

- We need support systems to connect people to each other and to timely assistance.
- There needs to be choice, it can’t be forced on someone and it must be easy to use.
- There is a need for ‘holistic’ assessment of all aspects of a person’s life.
- Carers and families often felt reassured knowing someone else was involved.
- Frictions and worries can be reduced around technology enabled medication support – people calm down when less worried about something.
- We need to reduce the risk of delaying requests for help. With telecare I hear people say “I don’t want to bother anyone, “it’s very late” or “I’d rather wait for my carer”
- Need easy access to a whole range of information and that’s where technology can play a part for carers.
- Want to talk to professionals who are well informed, not batted around, who have access to the right information, that they need to be technology savvy and aware of the full range of technology to assist their lives.

Technology enabled care is not a replacement for personal support but it can help provide reassurance just to check someone is up and about, manage risks associated with falls, or to give someone confidence that someone is there for them at all times, and there is someone to talk to.

3. What technology is out there to support carers?

Technology solutions for everyday life

We use a range of technology enabled solutions in our everyday lives:

- Internet for information, online shopping and banking.
- ‘Apps’ for clever living: travelling, planning, news, events, access council services, health monitoring, turning on our heating!
- Smart phones, mobile and ICT systems for remote working.
- Skype and video conferencing for real-time communication at a distance.
- Facebook for keeping in touch.

However, these tools, which are commonly used in many aspects of our everyday lives, do not consistently figure in our thinking when it comes to providing informal care. This is the first thing that needs to change when we think about supporting carers through technology enabled care services.
Types of technology enabled care and support services

Telecare

- Telecare is a system of monitors and sensors which can include a basic alarm service, able to respond 24/7, e.g. if someone has a fall. It can include sensors such as motion or fall detectors and fire and gas alarms that trigger an alert to a response centre staffed 24 hours a day, 365 days a year. It can include location devices that can find someone, e.g. if someone with dementia leaves their home.

Telehealth

- Telehealth supports people with long-term health conditions, by enabling them to measure their vital signs such as heart rate, blood pressure, oxygen saturation and temperature in their own homes, on a daily basis. An easy to use monitor and supporting medical devices relevant to the patient’s condition are installed in their home, and the patient simply answers a series of tailored questions about their symptoms when prompted by the monitor. The information is automatically sent to a monitoring centre for technical and clinical triage. If results are outside of parameters set for that individual, their clinician will be alerted.

Telemedicine

- Telemedicine provides remote video consultations between healthcare professionals and patients either in patients’ own homes, nursing homes, hospitals to GPs or hospitals to prisons. It helps to reduce patients’ lengths of stay in hospital and also supports care outside hospital, including early discharge, or avoids unnecessary visits and admissions to hospital. Skype is also a way to have a spoken conversation with someone over the Internet using the software application but is less secure than telemedicine.

Mobile apps

- Mobile devices and apps are increasingly being used to look after one’s health, wellbeing and fitness. Apps can be downloaded to monitor the number of walking steps, food intake, mood, support you to stop smoking or link with health devices to monitor blood pressure and weight. Apps can also be used to access information and advice and access council services. Carers UK also has developed an app, Jointly, increasingly used by carers to manage care of someone by linking up with others in a network.
Online services

Assistive technology

- Assistive technology is an umbrella term that includes assistive, adaptive, and rehabilitative devices for people with disabilities and also includes the process used in selecting, locating, and using them. Assistive technology promotes greater independence by enabling people to perform tasks that they were formerly unable to accomplish, or had great difficulty accomplishing, by providing enhancements to, or changing methods of interacting with, the technology needed to accomplish such tasks. It includes things such as computer aids, electric devices, eye-gaze and head trackers, wheel chairs, communication aids or medication reminders.

- Booking services – e.g. Hertfordshire Crossroads were pioneers in developing services where carers could “book themselves a break”.

- Matching services: several councils have developed “marketplaces” of services, e.g. Birmingham, Wigan and Hertfordshire – where people looking for assistance can advertise but also search for people providing assistance. Not-for-profit and community interest companies are also increasingly providing new mechanisms for people to find care.

- Forums, chatrooms and counselling. With email and online forums becoming a very familiar part of life for many and a preferred method of communication, these different ways of providing support are changing and are potentially low cost. Many organisations run different forums. Carers UK’s forum (www.carersuk.org/forum) is peer led – by carers – supporting other carers. Outcomes from the Forum suggest that it reduces isolation, helps people find tips and solutions. Friendships and even marriages have been built through the Forum. Other organisations have developed online counselling – such as that trialled by Timebank and more organisations are developing online advice sessions.
Life at your fingertips – what technology enabled care can provide

### Main issues carers face

<table>
<thead>
<tr>
<th>Stress/anxiety – constant pressure (physical and emotional)</th>
<th>Support 24 hrs a day, always there, for example sensors that will alert if taps or the gas has been left on, and turn the gas off automatically.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inability to have regular breaks/respite care.</td>
<td>Allows freedom to go out to shops, visit friends.</td>
</tr>
<tr>
<td>Worsening health of the carer.</td>
<td>Preventative nature of telecare/telehealth has been proven to reduce level of hospital admissions.</td>
</tr>
<tr>
<td>Getting to grips with medication.</td>
<td>Medication reminders, for example for people with memory difficulties.</td>
</tr>
<tr>
<td>Sleeplessness = lack of concentration.</td>
<td>Bed sensors alleviate the worry of epilepsy, enuresis, walking about, falls.</td>
</tr>
<tr>
<td>Isolation and loneliness.</td>
<td>Response centre is there for you to talk to, 24 hrs a day. Telecare allows you to get out and about. Also links to apps and online chatrooms.</td>
</tr>
<tr>
<td>Obtaining information easily to enable carers to live their lives.</td>
<td>Apps, easy access to web, staff being well informed about what is available.</td>
</tr>
</tbody>
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### How technology enabled care can help

- **CONNECTED**
  - with internet access and telephony
- **SECURE**
  - with video door entry and access control
- **INDEPENDENT**
  - help only when you need it
- **PROTECTED**
  - with environmental telecare sensors
- **ASSURED**
  - in a home that will evolve with you
- **IN CONTROL**
  - easy repair reporting and calendar management
- **SAFE**
  - with help available 24 hrs a day
- **WELL**
  - self care with health apps and telehealth
- **FULFILLED**
  - with social events and access to your community
4. How does technology support carers?

Real life case studies

A: Lucy is a working carer supporting Mum who lives with dementia and struggles with medication and memory issues

- More than 3 million people – one in nine of the workforce in the UK – juggle the responsibilities of caring and paid employment.
- 10% care for someone with dementia.

CHALLENGE

- Lucy works full time but cares for her mum, Val, who has early onset dementia.
- Val was taking lots of medication and due to her memory problems, was either overdosing or not taking her medication at the right time. There was a serious incident where overdosing on warfarin, which could have led to blood loss if she had cut herself.
- She also was prone to leaving the gas fire unlit which was a constant worry.
- Lucy took all Val’s medication away and hand delivered it herself at the correct time. Val also needed weekly hospital visits due to fluctuations in her condition.
- It was proving difficult getting time off work and her bosses were beginning to complain. Val was becoming increasingly stressed and tired both at work and at home.

SOLUTION

- Val was given a monitored medication dispenser, linked to a telecare home unit and 24/7 monitoring centre which dispenses her tablets and provides audible and visual alerts each time Val needs to take her medication. If Val doesn’t access her medication, an alert is raised to the monitoring centre who let Lucy know and she speaks to her Mum to talk her through what to do, however if she sounds confused she will also pop home from work.
- A monitored temperature extremes and gas detector were also made available should there be a gas leak or potential fire ensuring quick help on hand.

OUTCOMES

- Val’s condition has stabilised and she only needs monthly hospital visits.
- Lucy: “It’s such a relief, knowing that Mum is taking the right medication at the right time, I’ve even been able to have a short holiday for the first time in years.”
B: Family supporting Dad who is now struggling to cope on his own with various health conditions

• 3 in 5 people will be carers at some point in their lives.

CHALLENGE
• My Dad has been on his own since Mum died 3 years ago. At 79, he’s got a heart condition, incontinence, is generally very frail and unable to get around the house, even with his walking frame and we thought we’d lost him three times.
• My sister works full time as a teacher and has taken on the largest proportion of caring for Dad as she lives nearby. My brother lives down South and I work long hours.
• My sister is finding it very difficult juggling her job with caring for Dad – calling round at 6.30am to get him out of bed and give him his breakfast, calling by at lunchtime to feed him and leaving a flask of tea for the afternoon and again at dinner time.
• In addition, the district nurses visit regularly to give him warfarin, change his catheter and dress his ankle.
• We worry a lot about his health and the last straw was when he fell out of bed and had been unable to move all night. My sister thought the only solution was for her to give up her job to look after Dad full time.

SOLUTION
• We got Dad a telecare package and pendant and in first four weeks he’d used it twice. The first time was when he’d fallen in the evening and within minutes the Careline had called my sister who was round to see him straight away. However the second time he fell awkwardly and unfortunately his arm was twisted around his back, so he couldn’t reach the pendant on his wrist. My sister visited the next day and called the ambulance and he spent quite a bit of time recuperating. I’ve now suggested we get a bed sensor installed.

OUTCOMES
• The whole family feels so much more secure and has peace of mind that should dad need help, they’ll know about it straight away. My sister was seriously considering giving up work or going part time and now she feels she doesn’t have to as the burden has been shared.
• I think the telecare is brilliant and although my dad was reluctant at first, he knows it relieves the worry for us.
C: Single parent supporting two children with learning disabilities

- Almost 390,000 carers report being in bad health.
- 58% of carers look after someone with a physical disability.

CHALLENGE
- Lisa is a single parent to Chris and Elliot, both of whom have learning disabilities. They’re boisterous boys and she’s finding it harder to cope as they get older. It’s also much more difficult to make ends meet financially.

- Chris will be leaving school soon, and he’d like to live independently but that seems a distant dream. Lisa worries about what would happen if she’s no longer able to care for them.

SOLUTION
- The family were provided with a Lifeline home unit and carer pager. The unit receives alerts from sensors around the home. It notifies Lisa via a pager when she’s at home, and a monitoring centre when she isn’t.

- Bogus caller button – Lisa’s sons can raise an alert at the local monitoring centre if they answer the door in her absence.

- Bed occupancy sensor – lets Lisa know if one of the boys gets out of bed at night and doesn’t return safely after a short while.

- Property exit sensor – tells Lisa if one of the boys leaves the house in the evening.

- Heat detector – detects a rapid rise in temperature in the kitchen, indicating a possible fire.

OUTCOME
- Technology has enabled the family to stay together, Lisa is able to get a good night’s sleep for the first time in years.
D: Supporting a partner with a life changing physical disability

- 57% carers were helping the person they care for with their mobility – getting in and out of bed, moving around or getting out of the house.

**CHALLENGE**
- Six months ago Maria’s partner, Tim, was involved in a serious motor bike accident, which has resulted in him having to use a wheelchair. Tim has just come out of hospital and Maria’s been off work for several weeks to be with him, but her boss needs her back at work, and they need the money. Tim is fiercely independent and doesn’t want Maria doing everything for him – in fact he’d much rather she was back at work. He’s sleeping downstairs in the living room at the moment.

**SOLUTION**
- A Lifeline home unit and carer pager were installed. The unit receives alerts from sensors placed around the home. It notifies Maria via a pager when she’s at home, and a monitoring centre when she isn’t.
- Minuet watch – a wrist worn watch which also enables Tim to call for help if needed.
- Chair occupancy sensor – raises an alert if Tim falls out of his wheelchair.
- Bed occupancy sensor – lets Lisa know if Tim falls out of bed, enabling her to have a good night’s sleep without checking or worrying.

**OUTCOME**
- Maria and Tim’s relationship is much improved and Tim has his independence back.
E: Supporting a husband with lung disease and hospital stays

- 75% of carers said it was hard to maintain relationships and social networks because people do not understand the impact that caring has.

CHALLENGE
- Denise’s husband Jon lives with Chronic Obstructive Pulmonary Disease, and has had several hospital stays. Denise is constantly anxious about him. She doesn’t drive, so when he’s in hospital she has to take two buses and travel for over an hour to visit him. Although Denise tries to reassure Jon, she’s worried about the future.

SOLUTION
- Blood pressure monitor, thermometer and pulse oximeter – these devices enable Jon to easily take his blood pressure, temperature and blood oxygen levels and pulse rate at home, which are then transmitted wirelessly to the mymedic unit.
- mymedic telehealth unit – receives the readings from the medical devices above and transmits this data, along with answers to the questions Jon answers about his symptoms, to the monitoring centre for technical and clinical triage. A nurse or GP will then act on any readings that are too high or too low, whereby minimising the trips to hospital.

OUTCOME
- Telehealth enables Jon to take his vital signs daily, allowing any problems to be detected early, and helping to reduce admission to hospital. This also gives Jon and Denise reassurance that his condition is being closely monitored.
F: Hearing Loss and frailty supported

- Action on hearing loss estimates that there are more than 10 million (1 in 6) people in the UK with some degree of hearing impairment or deafness.

CHALLENGE
- Mrs Graham is a frail, older person receiving support at home from a care agency since her husband died.
- Mrs Graham has a hearing impairment, making it a real struggle for her to use the phone – this left her feeling increasingly isolated as her family doesn’t live locally.
- In addition, her social worker felt she was at a high risk of falling.

SOLUTION
- Amplified phone with pre-programmed photo contacts.
- Telecare enabled wrist-worn falls detector.

OUTCOME
- A two-week trial of the photo contacts phone proved very successful and Mrs Graham’s family decided to purchase the phone once the trial was over.
- The phone let them communicate easily with Mrs Graham, something that wasn’t possible on a standard telephone.
- The wrist-worn falls detector raises an alert with the Safe and Sound service (on a 24-hours-a-day basis), who are responsible for any physical response. It has given Mrs Graham and her family peace of mind and has meant that no increase in Mrs Graham’s domiciliary care is required.
- In addition, the effect of the amplified telephone has reduced Mrs Graham’s isolation and allowed her to continue to live independently.
G: Supporting a young adult with learning disabilities to live independently

• Young adults with a learning disability often find accessing higher education difficult as they do not have 24/7 support available to them if they require it.

CHALLENGE
• Martha’s seventeen year old son Graham lives with autism and is preparing to move to higher education.
• Martha is anxious about Graham’s ability to cope on his own as she does the majority of household tasks he will need to carry out when living away from home.
• Martha wants Graham to be independent and does not want to constantly be in contact and instructing Graham when he is at university, however she is worried about the impact of living independently and wants to ensure Graham has proper support to live well.

SOLUTION
• A smart phone programmed with an independent living and skills programme – this application helps Graham to keep to a routine, make decisions about in a logical way about what he should do when he doesn’t have guidance, and walks Graham through day-to-day activities such as cooking and cleaning.
• Martha can view when Graham is using the device and can see that he is looking after himself.
• She can also be contacted directly from the smartphone if the decision making application chooses her as a response to a difficult situation.
• New tasks and walkthroughs can be added to the app any time Graham requires a new skill for his day-to-day life.

OUTCOME
• Telecare apps help Graham to live independently, allowing him to follow step by step information that is personally tailored to his needs and to make important decisions reducing his levels of stress.
• This also gives Martha the reassurance that her son is living well and that he can access help when he needs it.

H. Keeping in touch

As well as these ways that technology enabled care can support carers, there is an app that can help keep people in touch.

**CHALLENGE**

- Looking after someone can be so complicated.

**SOLUTION**

- Carers UK’s Jointly is an innovative mobile and online app designed to support carers.
- It makes your caring a little easier, less stressful and a lot more organised by making communication and coordination between those who share the care as easy as a text message.
- With Jointly you can create a circle of care for the person you are looking after. Once you have set up your Jointly circle you can start using Jointly to organise care.
- You can use it on your own or you can invite other people to join you and share the care.

**OUTCOMES**

- What if something happens to me? Then everything being in my head is no good to anyone. This app will enable me to keep everyone in the loop.
5. Top 5 things advisers and commissioners need to challenge when looking at technology enabled care to help support carers

At the workshop, discussion took place about carers’ concerns about technology and this has been described below under five headings.

1. Negative perceptions about technology

There are still a lot of negative perceptions in the community associated with technology: eg it increases social isolation and loneliness; Skype leads to family and friends using it as an excuse not to visit as much; it shouldn’t be seen as an end in itself. In fact, some technology actually can work extremely well to reduce loneliness as there will be access to a person and support at all times.

Perceptions of cost can also put people off, even though the benefits in the long run far outweigh the costs, but for those on low incomes this could be a big issue. There needs to be awareness of the likely cost to install and run it, to cover the risks of repairs and breakdowns, ease of maintenance and insurance.

Providing the facts, letting carers try products, and carers talking to each other where they’ve had good experiences can help to overcome this particular problem. It’s essential that staff providing advice and support don’t hold negative perceptions about technology too – and they could also benefit from this.

2. Access to technology

A lot of people just don’t have smartphones and tablets to use apps. Access to a mobile signal and the internet is variable, particularly in rural areas. Not everyone is digitally included. There could be genuine concerns about reliability and worry if you lose it or break it.

Not all technology solutions require access to smartphones and mobile signals. There are some very useful, simple technologies out there that could help. The percentage of people with smartphones and tablets is increasing, including for older people and it’s important to ensure that options are provided to everyone.

3. Understanding the benefits to me

The perceived utility needs to be taken into account – will it work, will it do what I want it to do, will it deliver the outcomes around things that bother me, respond to my care and support needs or their carers: how does it affect the balancing of risks?

West Sussex local carers group is doing some work with tracking devices. A woman has epilepsy, occasionally gets lost and periodically forgets where she is. So a wrist worn bracelet is really helping her. Instead of describing the technology as a tracking device, it’s sometimes better to describe it in words that explain the outcome, eg as something that can enable you to go out on your own and makes sure you don’t get lost.

As well as carers, all the staff commissioning and advising carers should understand the benefits of different technologies and build in technology advice as part of a routine discussion about the support available.
4. Lack of options and awareness

Knowing what's available can create a very confusing picture. For instance, there are hundreds of apps out there – the “find me” app could be life changing. It's often better to have the ability to see it, touch it, see it working in situ, within a reasonable timescale and in a convenient location.

Information needs to be available conveniently and in a reasonable time frame and be provided by someone carers can trust, e.g. an occupational therapist, GP or carer. Carers UK has developed a series of guides on its website about technology which talks about different options and benefits which it is possible to download, link to or print out to hand to carers to help decide how to make a difference.

(www.carersuk.org/help-and-advice/practical-support/equipment-and-technology)

It is possible that carers will be picking from a menu of limited choices, particularly if they are self-funders. Commissioners ideally need to address technology and expand the range of options available, but if other options are not possible, then direct payments and additional advice or being clear about other options and private purchase should help carers make a decision.

5. Worries about the services surrounding the technology

Q. There can be concerns about how the technology in the home is connected to the monitoring centre.

A. The connection can either be via a telephone line in the home, by a mobile signal or wifi.

Q. There can be concerns about how good the monitoring centre is, and whether it will keep information secure.

A. All telecare monitoring centres follow strict rules in relation to security and you can ask if the centre is TSA accredited (Telecare Services Association).

Q. There can be concerns about who comes into carers’ homes to install the technology and whether they will make a mess. Also, there can be concerns about what happens if something goes wrong with the equipment or service.

A. While this will depend on what service is required, generally it is an accredited, CRB checked engineer who will minimise disruption.

Q. There may be concerns about the safety of the technology eg carers may be concerned they or the cared for could get a shock from it. What accreditations should be looked out for to prove the technology is good?

A. It is worth checking the product literature for standards.

It's important that anyone providing advice and support to carers is also aware of these concerns and encourages carers or supports them to find out the answers.
6. Key principles for local authorities – technology for carers

There are a number of key principles local authorities need to consider when providing technology enabled care services for carers.

- The statutory right to a social care assessment should always include a consideration for technology enabled care and other support services – “think tech”.
- All commissioners should develop simple, accessible and easy to find information that lists what technology is available to support carers in their local area. This information should also reference and include a link to this guide, as well as a link to Carers UK advice pages.
- Providers should take into account the specific needs of carers when developing care services that use technology.
- It is absolutely critical that all local authorities providing assistive technology should also provide corporate training on this topic – having information available is not enough. Local authorities using technology interventions alongside traditional care have been most effective, include strong training on offer to all client facing staff.

What else does “good look like” for technology in the context of the Care Act 2015?

- Do local authorities have leaflets for carers that are localised around technology?
- Do effective prevention care pathways have technology integrated?
- In terms of planning and delivery of services, are you making the most of the opportunities provided by technology? Carers UK surveyed several authorities who were developing different technology options for carers. One was providing a “digital offer” for carers. (www.carersuk.org/for-professionals/policy/policy-library/care-act-2014).

7. Further help and advice

Have you used the new ADASS resource below, to evaluate the effectiveness of your telecare service?

Developing a series of metrics for telecare – Improving quality and outcomes

- Every local authority has a telecare service which is doing great work to support people to live more independently and safely at home. But do we really know how well that service is performing and could it do more?
- This framework is primarily aimed at commissioners and providers of social care and health services who have identified technology enabled care services (TECS) as an effective way to support the health and social care needs of their local population.
- This document tries to answer the question ‘How do we measure the outcomes from telecare for people and the overall service?’ – and importantly support more people to live an even better life.

8. Information about the contributors

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**ADASS Carers Policy Network**

We would like to thank the members who attended the workshop and everyone else who contributed to this paper:

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