

ICT and unpaid carers of people living with dementia

Use, non-use and ideas for the future: Focus Group Findings

Jacqueline Damant

Derek King

Margaret Dangoor

Paul Freddolino

Bo Hu

Klara Lorenz-Dant

Raphael Wittenberg

Project overview

Workstream 1: Assessing ICT use

- Focus groups
 - ICT Types, functions
 - Effect of ICT use on carer; person living with dementia
 - Barriers and facilitators to use

Workstream 2: Evaluation of perceived effectiveness

- Survey
- 1-2-1 interviews

Workstream 3: assessment tool

- Matching technologies to personal needs and circumstances

Focus groups characteristics

6 focus groups

Total n= 32

n= 3-7 per group

Location

London: 2

North East: 2

South East: 1

Yorkshire and Humber: 1

Format

Online (Zoom): 4

In person: 2

Participant characteristics

- F/M: 26/6
- Age: 49 – 93 years

Relationship to person living with dementia

- Spouse/ex: 16
- Child/in-law: 15
- Other: 1

Residence of person living with dementia

- Co-resident with carer: 23
- Not co-resident: 6
- Care home: 6
- Other: 1

7 categories of ICT used by focus group participants

Type	Technologies mentioned	Type	Technologies mentioned
Mainstream ICT devices (hardware)	Mobile, landline phone Tablet, laptop computer Smart speakers (e.g. Amazon Echo) Radio Television, DVDs	Telecare	Pendant/wrist alarm Pressure mat Bed, fall, presence alarms
Mainstream ICT services -software, -applications -platforms	Internet, email, word processing Virtual assistant (e.g. Alexa, Siri, Google) Social media (e.g. Facebook, WhatsApp) Video conferencing (e.g. Zoom, Skype) Online exercise programmes	Telehealth -vital sign monitoring	Not mentioned
Accessible ICT devices	Dementia clocks Digital picture frames Large button mobile/landline phones	Other	Baby alarm Health care devices: hoist, bed, mattresses
Accessible ICT services	ALCOVE DUO Tracking/localisation services		

ICT functions used by carers, people living with dementia

- Consolidated to 7 functions
- **Greater** use of mainstream devices and services than accessible, telecare devices/services for most functions
- People living with dementia → little engagement with ICT

	<u>Carer</u>	<u>Person living with dementia</u>
Supporting ADLs		
Wellbeing, therapy, reminiscence	<ul style="list-style-type: none"> • Time management 	<ul style="list-style-type: none"> • Reminders
Monitoring and safety	<ul style="list-style-type: none"> • Reducing stress • Reassurance 	<ul style="list-style-type: none"> • Reminiscence • Physical fitness • Leisure
Care management	<ul style="list-style-type: none"> • Notification, alarm • tracking 	<ul style="list-style-type: none"> • Enhance independence
Social networking and communication	<ul style="list-style-type: none"> • Planning, coordination • Accessing services 	<ul style="list-style-type: none"> • Accessing care services
Occupation and work	<ul style="list-style-type: none"> • Family networking and support 	<ul style="list-style-type: none"> • Communication support
Education and information seeking	<ul style="list-style-type: none"> • Remote working 	<ul style="list-style-type: none"> • Skills and knowledge development

Examples of ICT used by function

Supporting ADLs

Carer

Time management →
• Monitoring ICT

Person w/ dementia

Reminders →
• **Virtual assistant**
• Dementia Clocks

Wellbeing, therapy, reminiscence

Carer

Reassurance →
• Telecare
• Localisation device
• **Camera + virtual assistant + mobile/laptop**

Person w/ dementia

Leisure, exercise, reminiscence →
• Social media
• Digital picture frame
• Radio
• TV, DVDs

Monitoring and safety

Carer

Notification
Tracking →
• Telecare
• Localisation device
• **Camera + virtual assistant + mobile/laptop**
• Baby monitor

Person w/ dementia

Independence →
• Telecare

Care management

Carer

Planning
Service access →
• Internet (online banking, shopping)
• **Zoom**

Person w/ dementia

Care service access →
• **Zoom**

Social networking and communication

Carer

• Mainstream ICT devices and services

Person w/ dementia

• **Zoom**
• ALCOVE
• Social media (with assistance)

Occupation and work

Carer

Remote working →
• Mainstream ICT devices and services

Education and learning

Carer

Skills development →
• Mainstream ICT devices and services
• Spoke online carer course (LA)

Impact of ICT-use on carers

Positive effects



Ψ-gical wellbeing

- Peace of mind
- Relief
- Pride
- Distraction

“Feeling modern!”

“Radio is on, otherwise it is dead silence all day”

Social wellbeing

- Gain support from network
- Comfort of human contact

Practical

- Caring simplified
- Cost saving (e.g. using WhatsApp)

Occupation

- Facilitates paid work
- Liberates time for other activities

Physical wellbeing

- Improved sleep
- Improved mood

Negative effects



Disappointment

→ loss of effectiveness at different stages of dementia

Frustration

“Sometimes there are about 5 buttons to press before you get what you want.”

Exclusion

e.g. from online meetings when fail to connect

Invasive

“The alarm of my phone was going off all the time. It was intense.”

Impact of ICT-use on people living with dementia*

Positive effects



“Radio [was on]...she liked it. She would start humming.”

ψ-gical wellbeing

- Independence
- Joy
- Feeling safe

Occupation

- Pursue leisure activities
- Entertained, engagement

Physical wellbeing

- Comfort
- Increased activity

Negative effects



Overwhelming, disorientating

“Gets confused: can’t distinguish reality from screen”

Loss of relevance, suitability as needs change

Unassessed, unmet needs
→ online care appointments

“Unless you introduce it at a very early stage, it’s too late”

Invasive
→ e.g. camera; voice from virtual assistant

* *...from carers’ perspective*

Barriers

Content

- Lacks relevance
- Inaccessible
- Exclusive, unfriendly, uninviting

“As soon as you learn something, there is something else. I can’t keep up.”

Capability

- Skills
- Exposure
- Awareness
- Disability

“I would describe myself as a bit wary and hesitant of anything technology-related.”

Confidence

- Fear
- Attitude

Cost

“Technology has its downsides and it can be quite expensive...”

Support

- Few/no relatives
- Low patience
- Lack of time
- Lack of staff (care homes)

“I don’t have time. My [spouse] never leaves my side. I don’t have enough time to sit and do the computer.”

Privacy

- Big brother
- Cyber security

Magic wand item

Magic Wand

- Simpler devices to navigate
- Passive 2-way communication device/service
- Remote control of devices and services
 - E.g. control TV in a care home

Important to consider:

- Different stages of dementia
- Adaptable services to personal likes and dislikes of person with dementia

Other emerging themes

Care home connectivity

- Lack of resident access to broadband
- Lack of equipment → impairs communication
- Poor interoperability of equipment

Carer mental wellbeing

- Challenging behaviour
- Depression
- Isolation

Limitations

Online Format

- Recruitment challenges
- Inaccessible for participants less ICT-confident

Carer support

- Carer responsibilities constrained availability

Thank you

Jacqueline Damant

j.damant@lse.ac.uk