ICT and unpaid carers of people living with dementia

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

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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

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

<table>
<thead>
<tr>
<th>Carer</th>
<th>Person living with dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Supporting ADLs</strong></td>
<td><strong>Wellbeing, therapy, reminiscence</strong></td>
</tr>
<tr>
<td>- Time management</td>
<td>- Reducing stress</td>
</tr>
<tr>
<td></td>
<td>- Reassurance</td>
</tr>
<tr>
<td><strong>Monitoring and safety</strong></td>
<td><strong>Care management</strong></td>
</tr>
<tr>
<td>- Notification, alarm</td>
<td>- Planning, coordination</td>
</tr>
<tr>
<td>- tracking</td>
<td>- Accessing care services</td>
</tr>
<tr>
<td><strong>Social networking and communication</strong></td>
<td><strong>Occupation and work</strong></td>
</tr>
<tr>
<td><strong>Education and information seeking</strong></td>
<td><strong>Remote working</strong></td>
</tr>
<tr>
<td>- Family networking and support</td>
<td>- Communication</td>
</tr>
<tr>
<td><strong>Skills and knowledge development</strong></td>
<td></td>
</tr>
</tbody>
</table>
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 →
    - Monitoring ICT
  - **Person w/ dementia**
    - Leisure, exercise, reminiscence →
      - Virtual assistant

**Monitoring and safety**
- **Carer**
  - Notification Tracking →
    - Monitoring ICT
  - **Person w/ dementia**
    - Baby monitor

**Care management**
- **Carer**
  - Planning Service access →
    - Internet (online banking, shopping)
  - **Person w/ dementia**
    - Independence →
      - Zoom

**Social networking and communication**
- **Carer**
  - Remote working →
    - Mainstream ICT devices and services
  - **Person w/ dementia**
    - Zoom

**Occupation and work**
- **Carer**
  - Remote working →
    - Mainstream ICT devices and services
  - **Person w/ dementia**
    - ALCOVE

**Education and learning**
- **Carer**
  - Skills development →
    - Mainstream ICT devices and services
  - **Person w/ dementia**
    - Spoke online carer course (LA)
Impact of ICT-use on carers

Positive effects

- Peace of mind
- Relief
- Pride
- Distraction

"Feeling modern!"

Social wellbeing

- Gain support from network
- Comfort of human contact

"Radio is on, otherwise it is dead silence all day"

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

<table>
<thead>
<tr>
<th>Psychological wellbeing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Independence</td>
</tr>
<tr>
<td>Joy</td>
</tr>
<tr>
<td>Feeling safe</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Occupation</th>
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<tbody>
<tr>
<td>Pursue leisure activities</td>
</tr>
<tr>
<td>Entertained, engagement</td>
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</table>

<table>
<thead>
<tr>
<th>Physical wellbeing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comfort</td>
</tr>
<tr>
<td>Increased activity</td>
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### Negative effects

<table>
<thead>
<tr>
<th>Overwhelming, disorientating</th>
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<tr>
<td>Loss of relevance, suitability as needs change</td>
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</table>

<table>
<thead>
<tr>
<th>Unassessed, unmet needs</th>
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</thead>
<tbody>
<tr>
<td>online care appointments</td>
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</table>

<table>
<thead>
<tr>
<th>Invasive</th>
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<tr>
<td>e.g. camera; voice from virtual assistant</td>
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*...from carers’ perspective*
<table>
<thead>
<tr>
<th>Barriers</th>
<th>Content</th>
<th>Capability</th>
<th>Confidence</th>
<th>Cost</th>
<th>Support</th>
<th>Privacy</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• Lacks relevance</td>
<td>• Skills</td>
<td>• Fear</td>
<td>• Few/no relatives</td>
<td>• Big brother</td>
<td>• Lacks relevance</td>
</tr>
<tr>
<td></td>
<td>• Inaccessible</td>
<td>• Exposure</td>
<td>• Attitude</td>
<td>• Low patience</td>
<td>• Cyber security</td>
<td>• Inaccessible</td>
</tr>
<tr>
<td></td>
<td>• Exclusive, unfriendly, uninviting</td>
<td>• Awareness</td>
<td></td>
<td>• Lack of time</td>
<td>• Lack of staff (care homes)</td>
<td></td>
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</table>

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

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

"Technology has its downsides and it can be quite expensive…"

"I don’t have time. My [spouse] never leaves my side. I don’t have enough time to sit and do the computer."
Important to consider:

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

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
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

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