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Conducting a study in adult social care during a pandemic: lessons from the MOPED study

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Disclaimer

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• The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.
About the project: the MOPED study

• To test two new questionnaires that are part of the Adult Social Care Outcomes Toolkit (ASCOT)

• The ASCOT questionnaires are used to collect information on the quality of life of people who use social care services and their carers

• ASCOT-Proxy and ASCOT-Carer
About the project: the MOPED study

1. Is the ASCOT-Carer a valid and reliable measure of the social care outcomes of carers of people with dementia?

2. Is the ASCOT-Proxy a valid and reliable proxy-report measure of the social care outcomes of people with dementia?

3. What factors are associated with the quality of life of people with dementia in the community (by proxy-report) and their carers?
About the project: the MOPED study

• 300 carers of people with dementia to take part in a survey (online or paper form)

Inclusion criteria:
A friend or family member of someone living with dementia, who:
➢ Lives at home (not in a nursing or residential care home)
➢ Uses at least one type of social care service
➢ Would not be able to answer a postal or online questionnaire, even with help.
Timeline

Start of the study: 09/09/2019

Application submitted to SC REC: 10/10/2019

SC REC approval: 14/01/2020

Pilot of the online survey: 27/01 until 27/02/2020

Start of recruitment: 02/03/2020

ADASS approval: 25/02/2020

COVID-19: 17/03/2020

SC REC meeting: 01/11/2019

HRA application submitted: 05/08/2020

HRA approval: 09/09/2020

End of the study: 08/09/2021

NHS recruitment: 15/10/2020

Paper questionnaire: 29/10/2020

End of recruitment: 30/04/2021
Key changes as a response to COVID-19

- Online survey only between March and October 2020
- Follow up data collection was halted completely: not possible to evaluate test-retest reliability
- Changes to recruitment pathways
## Lessons learned: Flexible approach to data collection

<table>
<thead>
<tr>
<th>Recruitment pathway</th>
<th>Before COVID-19</th>
<th>During COVID-19</th>
<th>Additional changes</th>
</tr>
</thead>
</table>
| The Join Dementia Research platform     | One of the pathways | Key recruitment pathway  
2872 invitations send between January and July 2020                             | Simplified recruitment  
Second follow up during Autumn 2020                                                |
| Carers’ organisations                   | Promoting the study  
Distributing the study packages | 10 organisations agreed to promote the study throughout July 2020              | Simplified adverts  
Additional advertising throughout September 2020                                    |
| Local Authorities                       | RG approval  
Promoting the study  
Distributing the study packages | 8 LA issued RG approval  
12 randomly selected LA (out of 152)  
LA selected based on interest from carers’ organisation |                                                                                |
| Social media (Twitter)                  | One of the pathways | PSSRU Twitter account May 2020                                               | Simplified adverts  
During July, twice a week                                                              |
| The NHS                                 | NA              | From October 2020 key recruitment pathway  
25 NHS sites                                                                           | 10 amendments                                                            |
### Lessons learned: one approach does not fit all

- Online vs paper questionnaire
- Anonymous approach vs targeted approach

<table>
<thead>
<tr>
<th>Survey mode</th>
<th>Recruitment</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>JDR</td>
<td>NHS</td>
</tr>
<tr>
<td>Postal</td>
<td>8</td>
<td>55</td>
</tr>
<tr>
<td>Online (Qualtrics)</td>
<td>165</td>
<td>85</td>
</tr>
<tr>
<td>Total</td>
<td>173</td>
<td>140</td>
</tr>
</tbody>
</table>
Lessons learned: crucial role of project partners

NIHR Clinical Research Network CPMS 44825
LCRN Kent, Surrey and Sussex Core Team

25 NHS sites across England

637 Carers

The Join Dementia Research

8 Local Authorities

10 Carers’ and other organisations

University of Kent: LSSJ Finance Team Design and print centre Estates postroom
Our Team

Professor Karen Jones
Co-Investigator

Ann-Marie Towers
Co-Investigator

Dr Stacey Rand
Chief Investigator

Della Ogunleye
Research Advisor

Aakta Patel
Research Advisor
Summary: lessons from the MOPED study

• A flexible approach to data collection

• Exploring recruitment pathways not considered at the start of the study

• More targeted approaches, e.g. contacting participants individually were more successful
Would you like to learn more?

Session 3a: Social Care

Dr Stacey Rand: Measuring social-care related quality of life of people with dementia and carers
Thanks for your attention!

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