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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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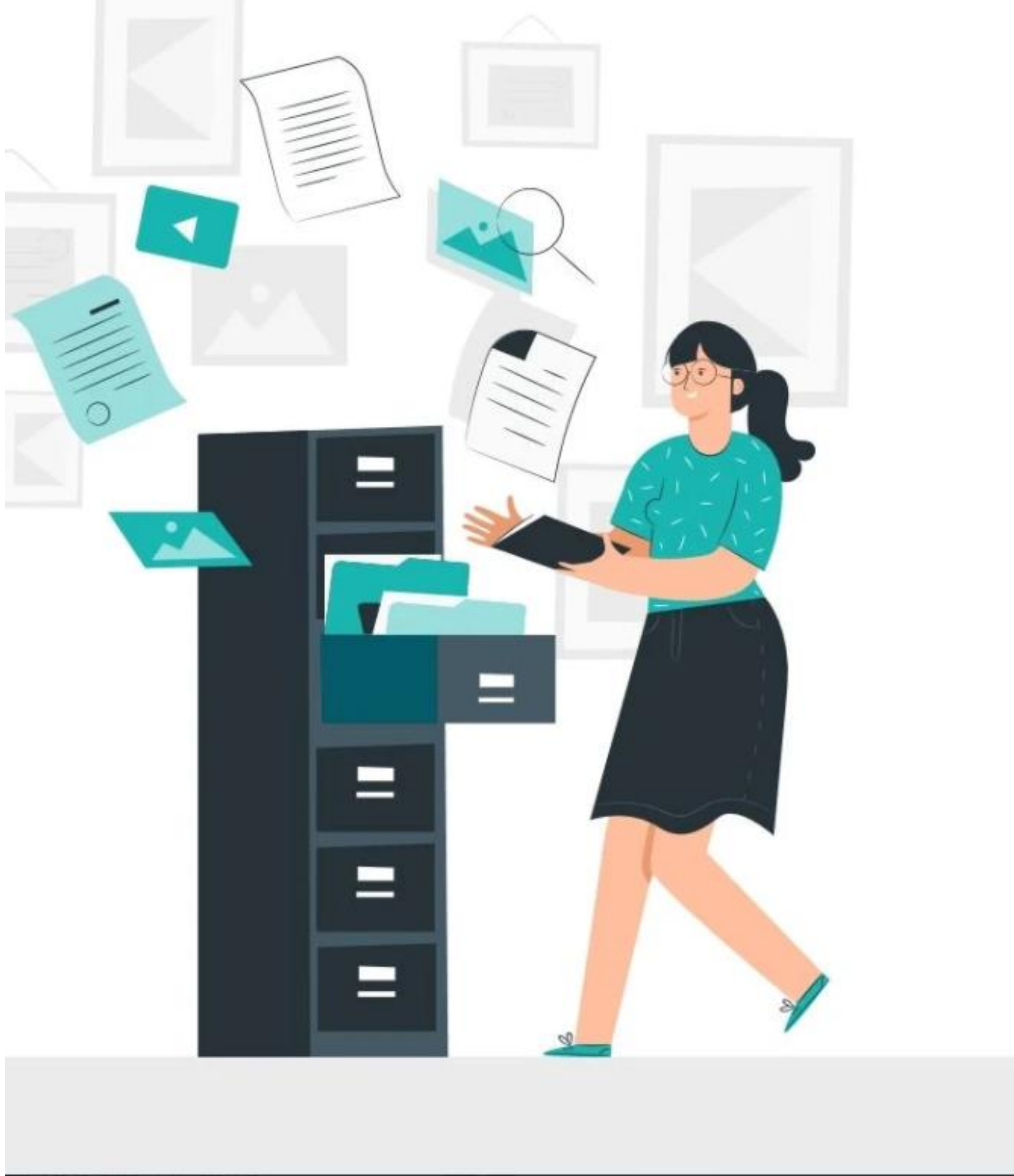
About the project: the MOPED study

- 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

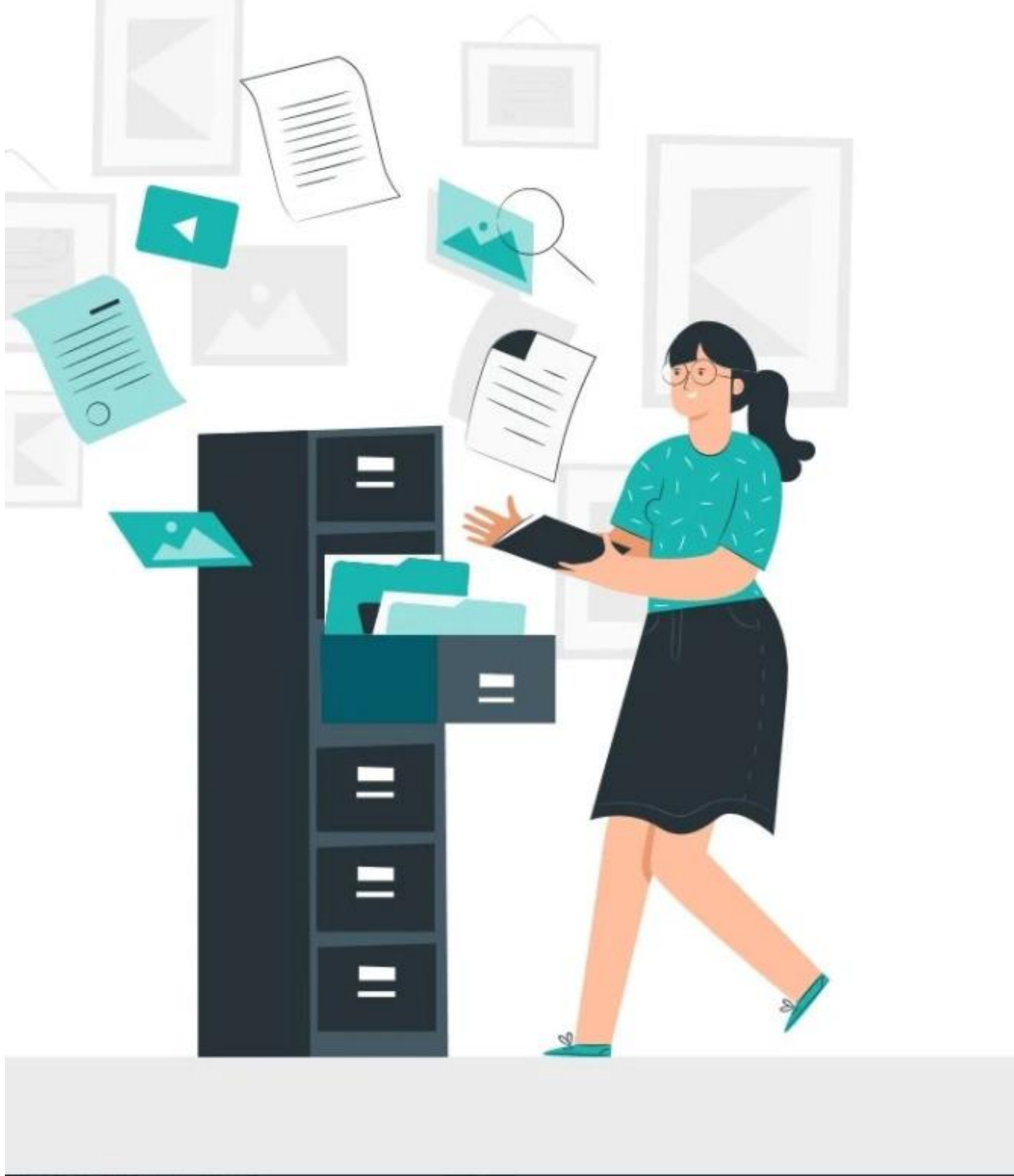


About the project: the MOPED study

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?

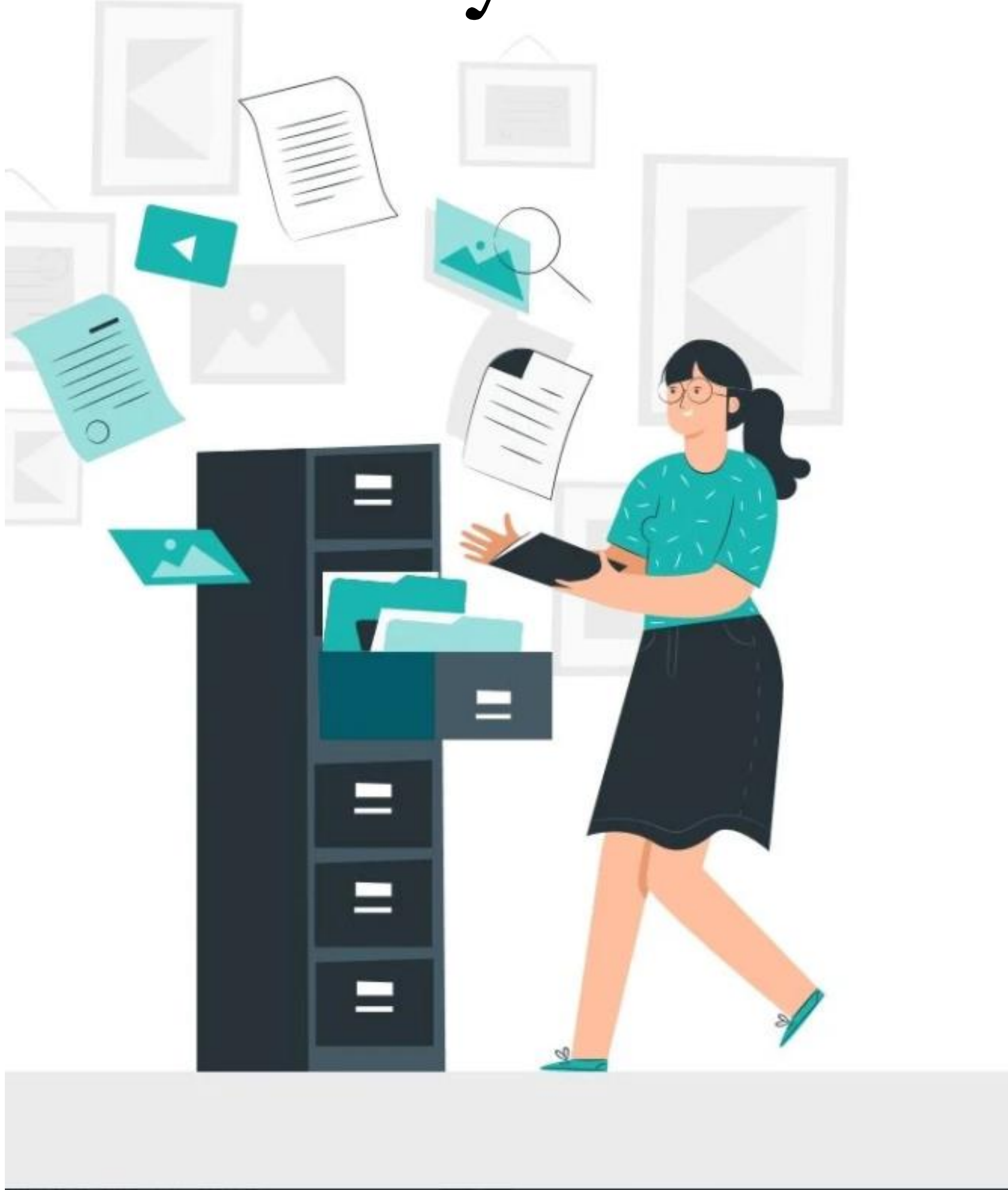


About the project: the MOPED study

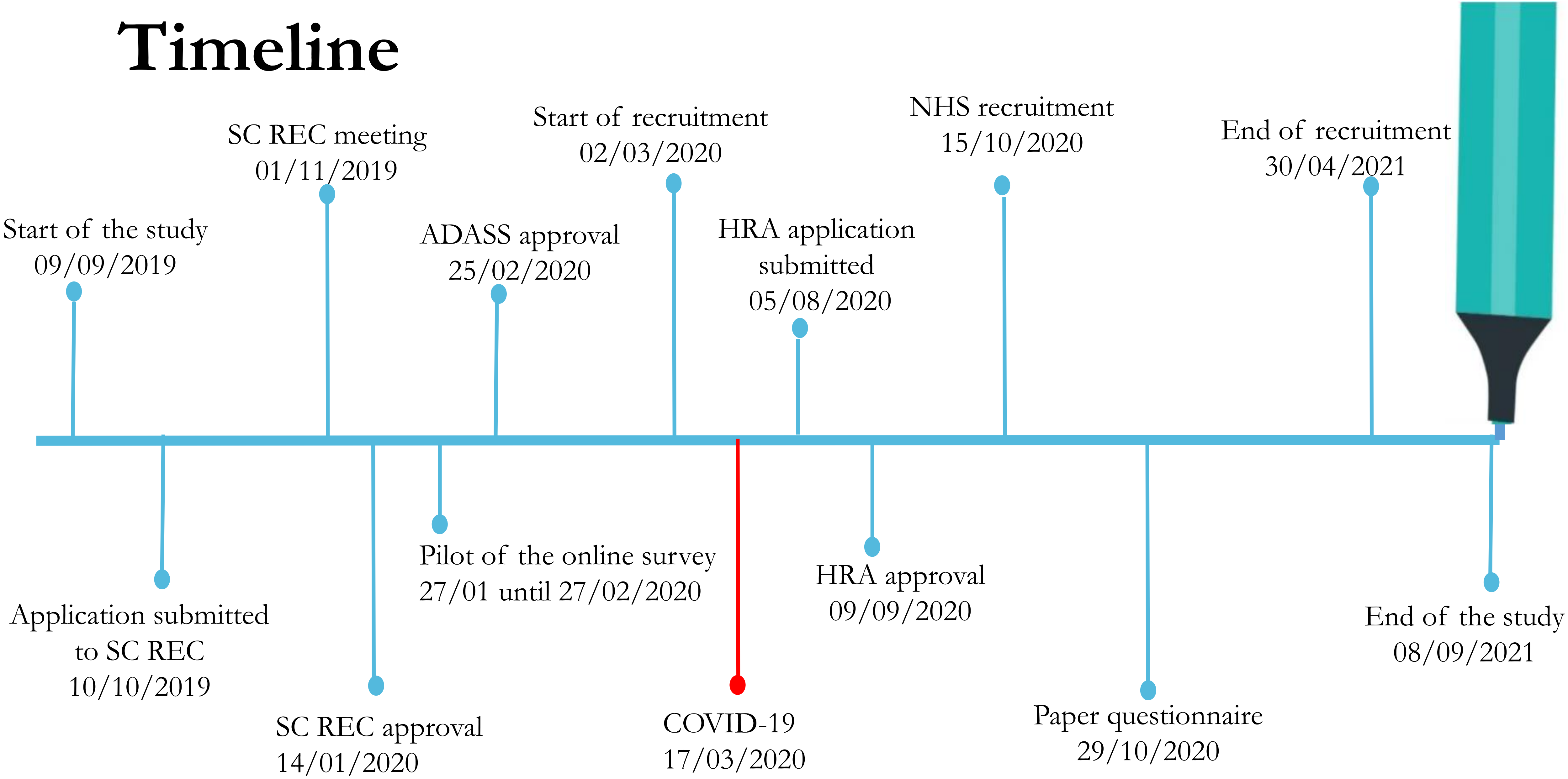
- 300 carers of people with dementia to take part in a survey (online or paper form)

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 meeting
01/11/2019

SC REC approval
14/01/2020

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

ADASS approval
25/02/2020

Start of recruitment
02/03/2020

COVID-19
17/03/2020

HRA application submitted
05/08/2020

HRA approval
09/09/2020

NHS recruitment
15/10/2020

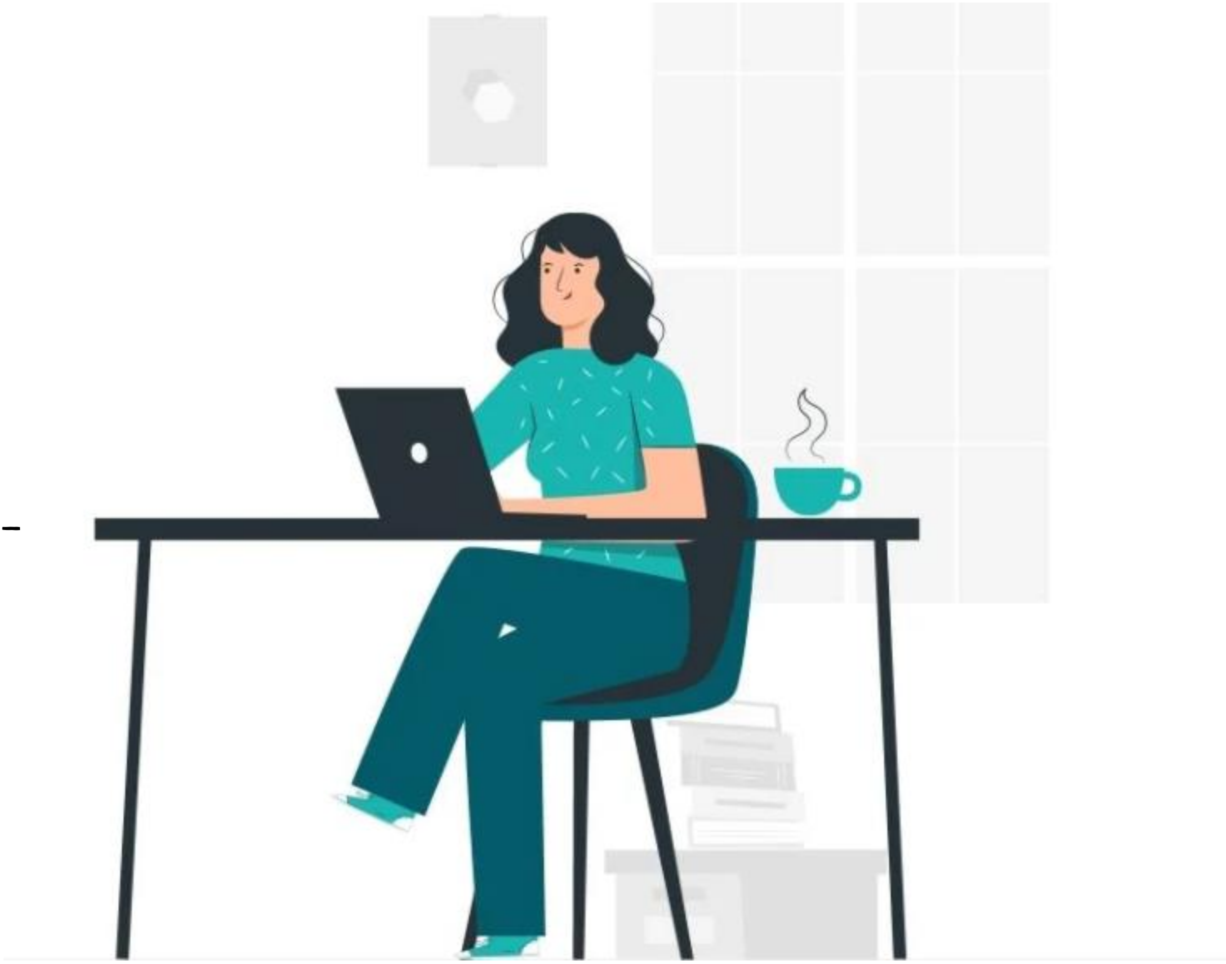
Paper questionnaire
29/10/2020

End of recruitment
30/04/2021

End of the study
08/09/2021

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

Recruitment pathway	Before COVID-19	During COVID-19	Additional changes
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

Survey mode	**Recruitment**		**Total**
	JDR	**NHS**	
Postal	8	55	63
Online (Qualtrics)	165	85	250
Total	173	140	313

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

Della Ogunleye
Research Advisor

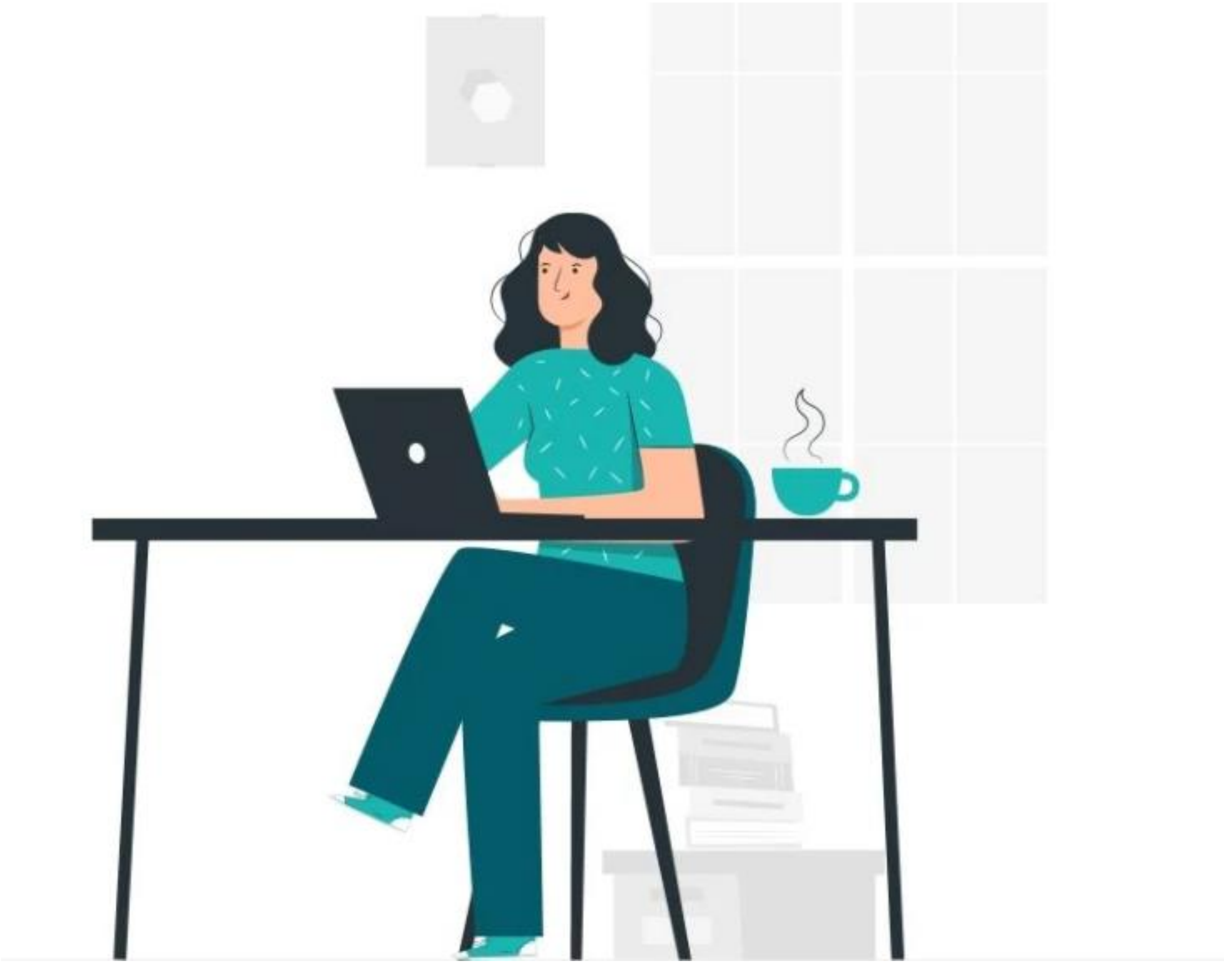
Ann-Marie Towers
Co-Investigator

Aakta Patel
Research Advisor

Dr Stacey Rand
Chief Investigator

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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