Challenges with online data collection methods amongst people with dementia

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Abbreviated abstract: Conducting research with People with Dementia (PwD) can be challenging due to their disease symptoms. Online methods have become the preferred option recently due to the COVID-19 outbreak. However, collecting data with PwD online requires robust strategies to observe, manage and support PwD and their engagement. A rapid review was undertaken to: i) identify online data collection methods that have been undertaken with PwD and ii) identify practical, technical, and ethical challenges associated with these approaches.

Related publications:

[1]Beuscher, L.& Grando, V. T. 2009. Challenges in conducting qualitative research with individuals with dementia. *Research in gerontological nursing,* 2**,** 6-11

[2]Irani, E. 2018. The Use of Videoconferencing for Qualitative Interviewing: Opportunities, Challenges, and Considerations. *Clinical Nursing Research,* 28**,** 3-8

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Challenges of doing online research with PwD

- Collecting data with PwD can be challenging due to their symptoms of anxiety, confusion, forgetfulness and fluctuating mental capacity[1]
- Researchers must prevent PwD from being exploited while safeguarding their well-being
- COVID-19 restriction on social distancing makes it impractical to collect data from PwD with traditional face-to-face methods.
- Collecting data online can be done without geographical and travel constraints[2]. However:
  - Older population and PwD have less access to the internet
  - Limited support can be provided if they are in distress due to the lack of physical proximity
  - Participants may not know how to use the technologies
- A rapid review was undertaken to identify challenges that were associated with doing online research with PwD

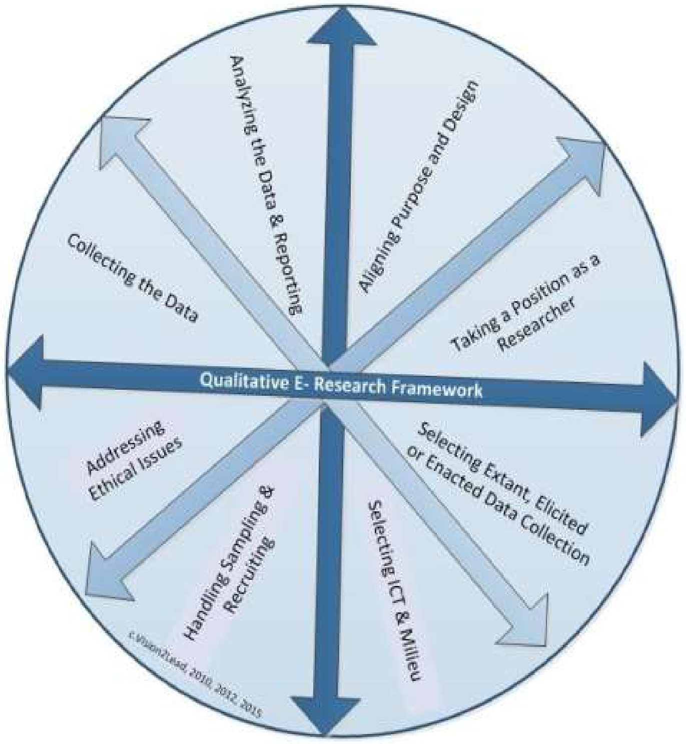

Fig 1. E-research framework. Taken from Salmons, J. (2016). *Doing qualitative research online*. 55 City Road, London: SAGE Publications Ltd doi: 10.4135/9781473921955

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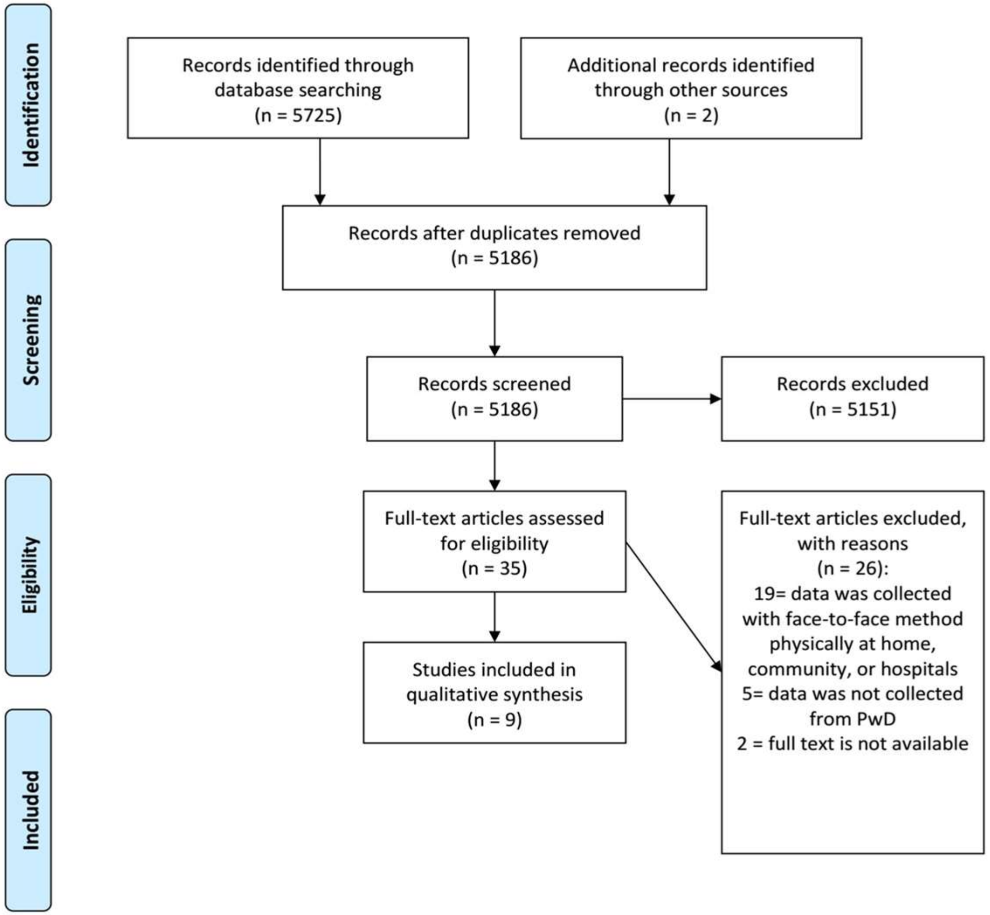
Methods

- A rapid review was conducted between March and June 2020, involving keyword searches of three databases and two grey literature databases: PubMed, CINAHL, PsycINFO, OpenSIGLE and OpenGrey
- 5,186 articles published between January 2013 - June 2020 were screened after duplicates removal. Thirty five articles went through dual screening process: the first screener's assessed 35 articles for eligibility; results of the screening were checked and confirmed by the second verifier. Nine articles remained for the analysis.
- A reflexive thematic analysis was conducted to identify practical, technical and ethical challenges in the included studies.



Records identified through database searching (n = 5725)

Additional records identified through other sources (n = 2)

Records after duplicates removed (n = 5186)

Records screened (n = 5186)

Records excluded (n = 5151)

Full-text articles assessed for eligibility (n = 35)

Full-text articles excluded, with reasons (n = 26):
19= data was collected with face-to-face method physically at home, community, or hospitals
5= data was not collected from PwD
2 = full text is not available

Studies included in qualitative synthesis (n = 9)

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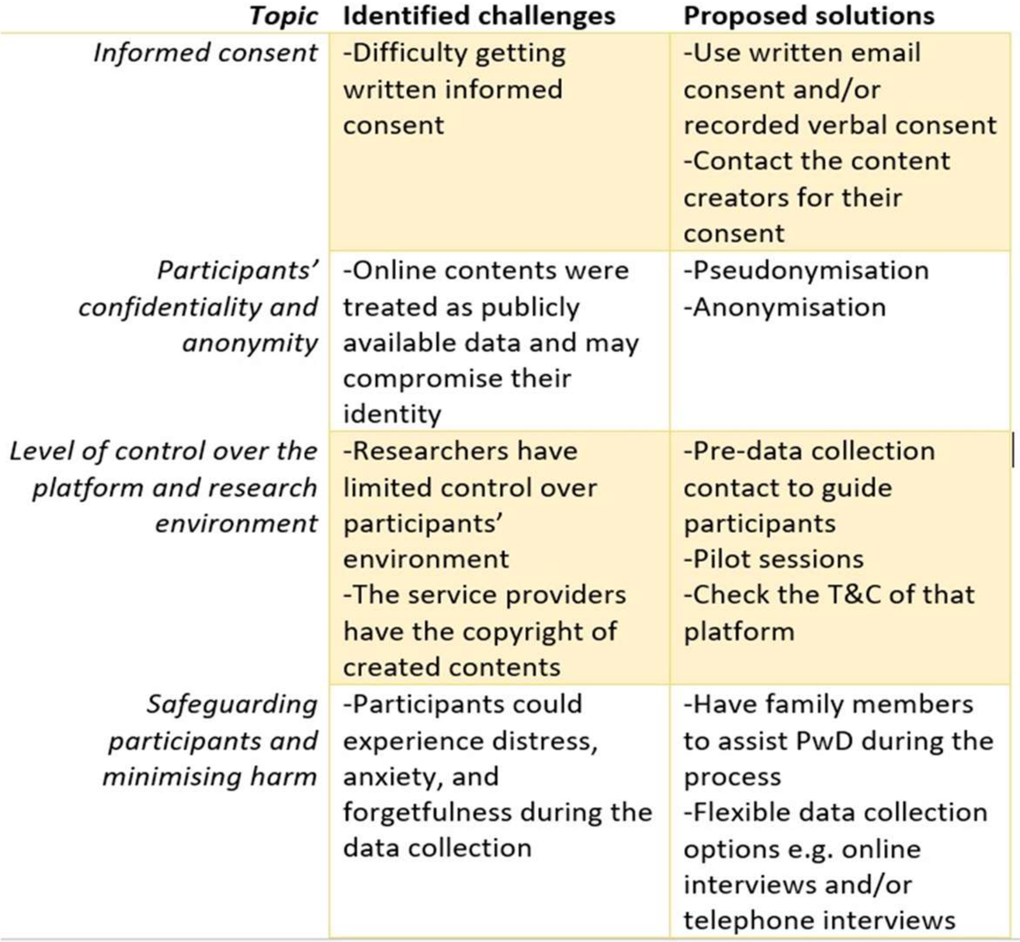
Results and Conclusions

- Both synchronous (real time) methods (online interviews, virtual clinical assessment) and asynchronous (anytime) methods (textual analysis from PwD's Twitter, blogs) were used
- Articles selected rarely discussed practical challenges of online data collection with PwD. Further research is needed.
- Identified ethical challenges are outlined in Fig 2.
- Technical challenges with synchronous methods was the need for extensive support for participants before and during the data collection. For asynchronous methods, challenges were difficulties around recruitment process and participant verification.
- Conducting online research with PwD is possible but:
    - Researchers must be proficient with the platforms to support participants
    - A traceable, valid consent is recommended
    - Extra time prior the data collection to inform, prepare and support participants is a must



Topic	Identified challenges	Proposed solutions
Informed consent	-Difficulty getting written informed consent	-Use written email consent and/or recorded verbal consent -Contact the content creators for their consent
Participants' confidentiality and anonymity	-Online contents were treated as publicly available data and may compromise their identity	-Pseudonymisation -Anonymisation
Level of control over the platform and research environment	-Researchers have limited control over participants' environment -The service providers have the copyright of created contents	-Pre-data collection contact to guide participants -Pilot sessions -Check the T&C of that platform
Safeguarding participants and minimising harm	-Participants could experience distress, anxiety, and forgetfulness during the data collection	-Have family members to assist PwD during the process -Flexible data collection options e.g. online interviews and/or telephone interviews

Fig. 2. Ethical challenges and proposed solutions

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