



PEARL

**Research with older people in a world with COVID-19: identification of current and future priorities, challenges and opportunities**

Richardson, Sarah J.; Carroll, Camille B.; Close, Jacqueline; Gordon, Adam L.; O'Brien, J; Quinn, Terence J.; Rochester, Lynn; Sayer, Avan A.; Shenkin, Susan D.; van, der Velde N; Woo, Jean; Witham, Miles D.

**Published in:**

Age and Ageing

**DOI:**

[10.1093/ageing/afaa149](https://doi.org/10.1093/ageing/afaa149)

**Publication date:**

2020

**Document version:**

Other version

**Link:**

[Link to publication in PEARL](#)

**Citation for published version (APA):**

Richardson, S. J., Carroll, C. B., Close, J., Gordon, A. L., O'Brien, J., Quinn, T. J., Rochester, L., Sayer, A. A., Shenkin, S. D., van, D. V. N., Woo, J., & Witham, M. D. (2020). Research with older people in a world with COVID-19: identification of current and future priorities, challenges and opportunities. *Age and Ageing*, 0(0). <https://doi.org/10.1093/ageing/afaa149>

All content in PEARL is protected by copyright law. Author manuscripts are made available in accordance with publisher policies. Wherever possible please cite the published version using the details provided on the item record or document. In the absence of an open licence (e.g. Creative Commons), permissions for further reuse of content should be sought from the publisher or author.

## **Supplementary Material: Survey Methods and Results**

### **Methods**

#### *Survey development and design*

The questionnaire was written with input from all authors. The final survey consisted of 11 questions: 5 multiple choice questions gathering demographic and occupational data regarding respondents, 5 free text options gathering opinions regarding research priorities and how research may need to adjust to a world with COVID. The final question was a free text option for any additional comments. The survey questions are given below.

#### *Survey administration*

The questions were uploaded to SurveyMonkey ([www.surveymonkey.com](http://www.surveymonkey.com)) and a weblink to the survey site was distributed along with an invitation to participate in the survey. The survey was advertised via professional networks connected to the authors, including the British Geriatrics Society, European Union Geriatric Medicine Society, Chartered Society of Physiotherapists in the UK, NIHR Clinical Research Networks for Ageing, Dementia and Neurodegeneration, and was widely shared on Twitter through the above organisations and through internationally connected influencers in geriatric medicine. Survey responses were fully anonymised and no identifiable information was collected. No ethical approval was required or sought for the survey. The survey was open to responses from anywhere in the world from 8<sup>th</sup> May 2020 to 16<sup>th</sup> May 2020.

#### *Data analysis*

Responses were downloaded from SurveyMonkey as Microsoft Excel files and were analysed in SPSS v24 (IBM, New York, USA). Open responses were divided into themes that emerged from the data, with no prespecified framework imposed. Responses were kept deliberately

broad to minimise the number of thematic categories. Categorisation was performed by SR and checked by MDW. Descriptive statistics on the respondents and the frequency of themes were generated; where a respondent had given duplicate or very similar responses within a question, the response was counted only once.

## **Results**

267 respondents completed the survey. Details on country, profession and specialty interest are shown in Table 1. Figures 1-4 show the frequency with which responses were given to the questions regarding research priorities, design and delivery. Tables 2-6 give subthemes and examples within each theme to give a sense of typical responses.

## Survey Questions

1. What country are you based in? England / Wales / Scotland / Northern Ireland / Other (free text)
2. Are you a: non-clinical academic / clinical academic / clinician
3. If you are a researcher, are you an: early career researcher (pre-doctoral or <5 yrs postdoctoral) / experienced researcher (>5 yrs postdoctoral) / not a researcher
4. Is your area of expertise: Dementia / Stroke / Movement disorders / Other geriatric medicine / Other (free text)
5. What is your profession: Doctor / Nurse / Physiotherapist / Occupational therapist / Other (free text)
6. How has the COVID-19 pandemic changed how research for older people is conducted in your organisation? (free text)
7. Regarding research on COVID-19 and older people, what three areas/topics should be prioritised? (free text)
8. How do you think the design of research studies for older people (not just for COVID) will need to change in a world with COVID (top 3 suggestions, free text)
9. How does the way we conduct research studies in practice (not just for COVID) need to change in a world with COVID (top 3 suggestions, free text)
10. What are the top three lessons you have learned as a result of the impact that COVID-19 has had on research for older people (free text)
11. Any other thoughts or comments you would like to share? (free text)

**Table 1. Details of survey respondents**

		N (%)
Country	England	162 (60.7)
	Wales	2 (0.7)
	Scotland	51 (19.1)
	Northern Ireland	6 (2.2)
	Other European	31 (11.6)
	Rest of world	15 (5.6)
Clinician / academic	Clinician, non-academic	89 (33.3)
	Academic, non-clinician	57 (21.3)
	Clinical academic	119 (44.6)
	Other	2 (0.7)
Research career stage	Early career researcher	67 (25.1)
	Experienced researcher	124 (46.4)
	Not a researcher	76 (28.5)
Area of expertise	Dementia	73 (27.3)
	Stroke	24 (9.0)
	Movement disorders	30 (11.2)
	Other geriatric medicine	98 (36.7)
	Other	42 (15.7)
Professional group	Doctor	163 (61.0)
	Nurse	21 (7.9)
	Physiotherapist	17 (6.4)
	Occupational therapist	3 (1.1)
	Speech and language therapist	1 (0.4)
	Pharmacist	3 (1.1)
	Dietician	4 (1.5)
	Psychologist	10 (3.7)
	Academic	26 (9.7)
	Other	19 (7.1)

Figure 1. Most common ways that COVID-19 has impacted on research for older people:

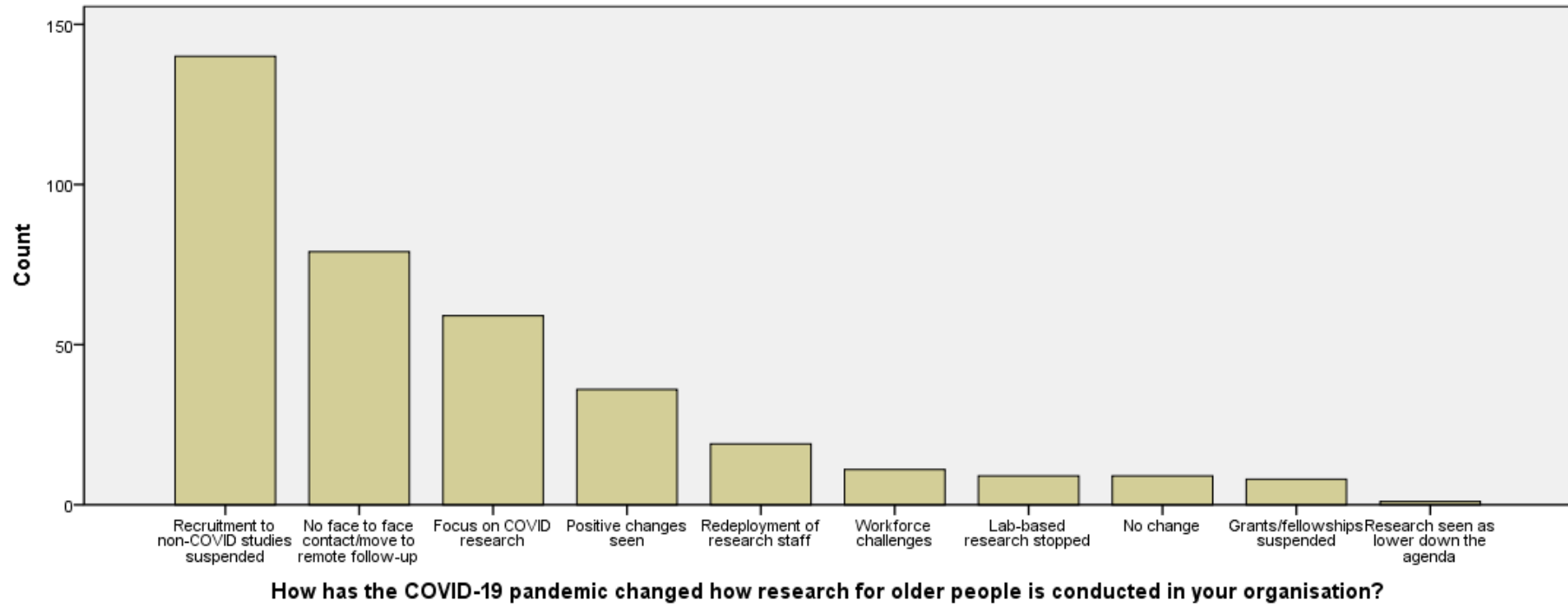


Figure 2. Most popular topics to prioritise for COVID-19 research:

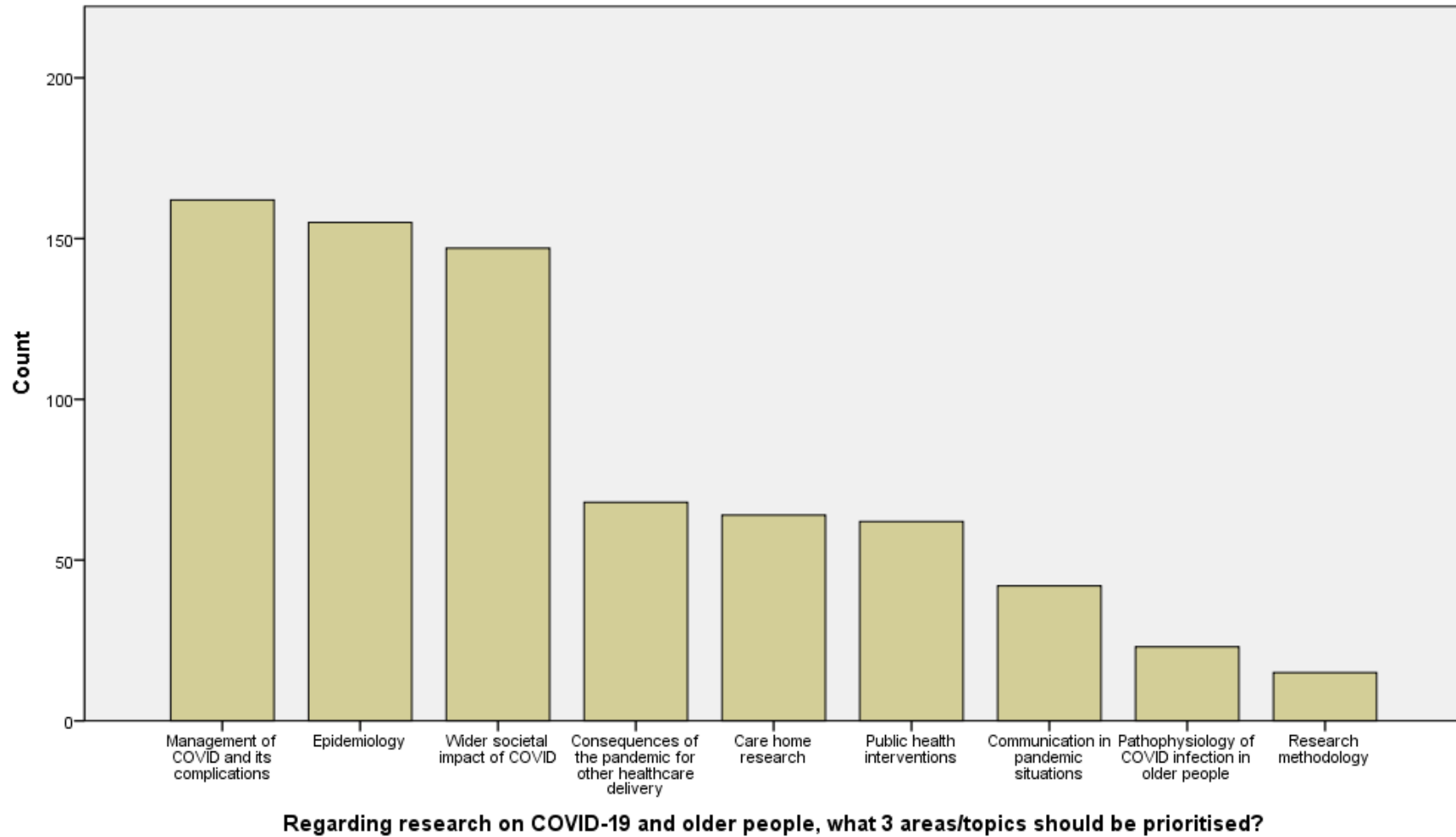


Figure 3. Most popular ways that research design needs to change in a world with COVID-19:

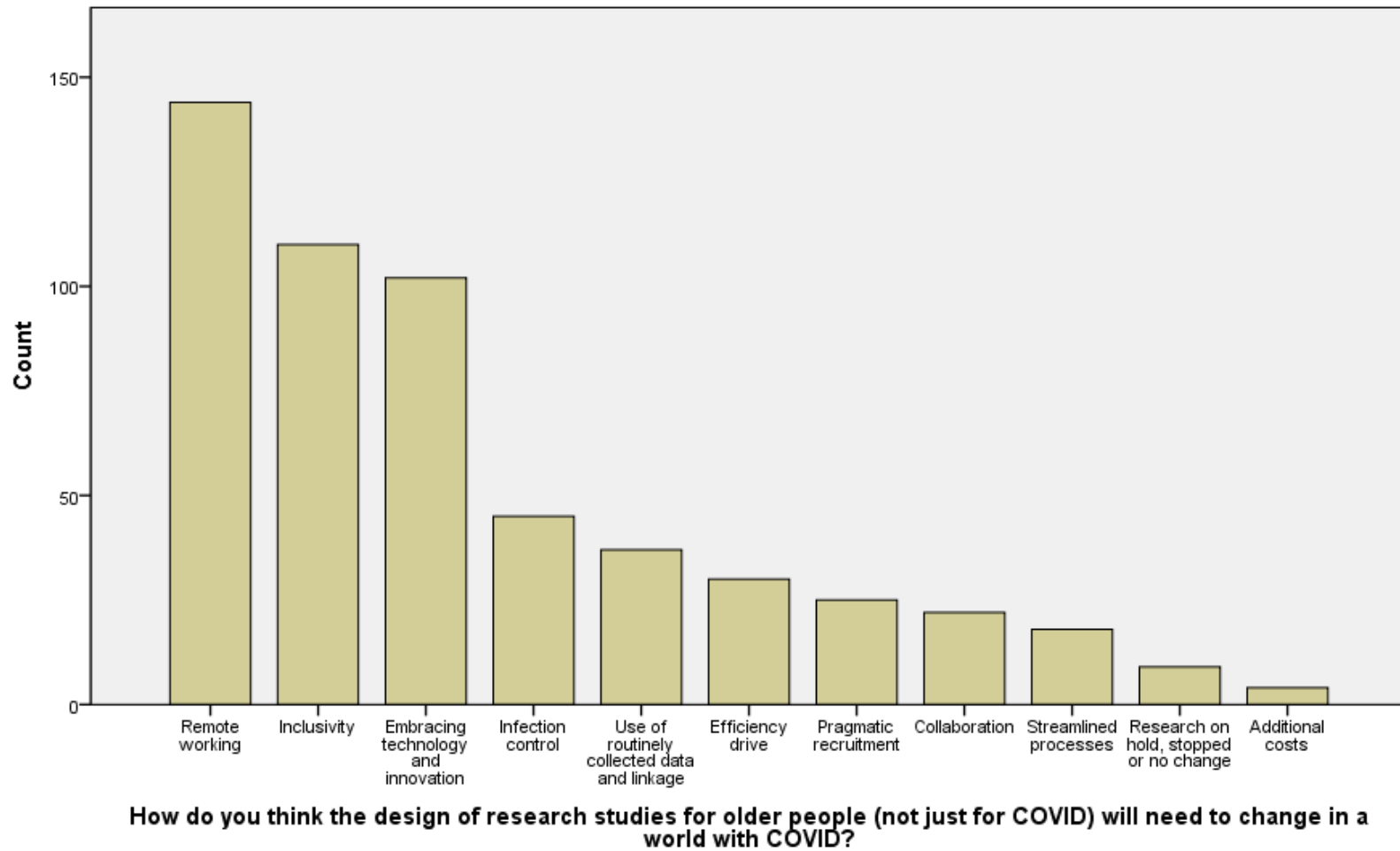
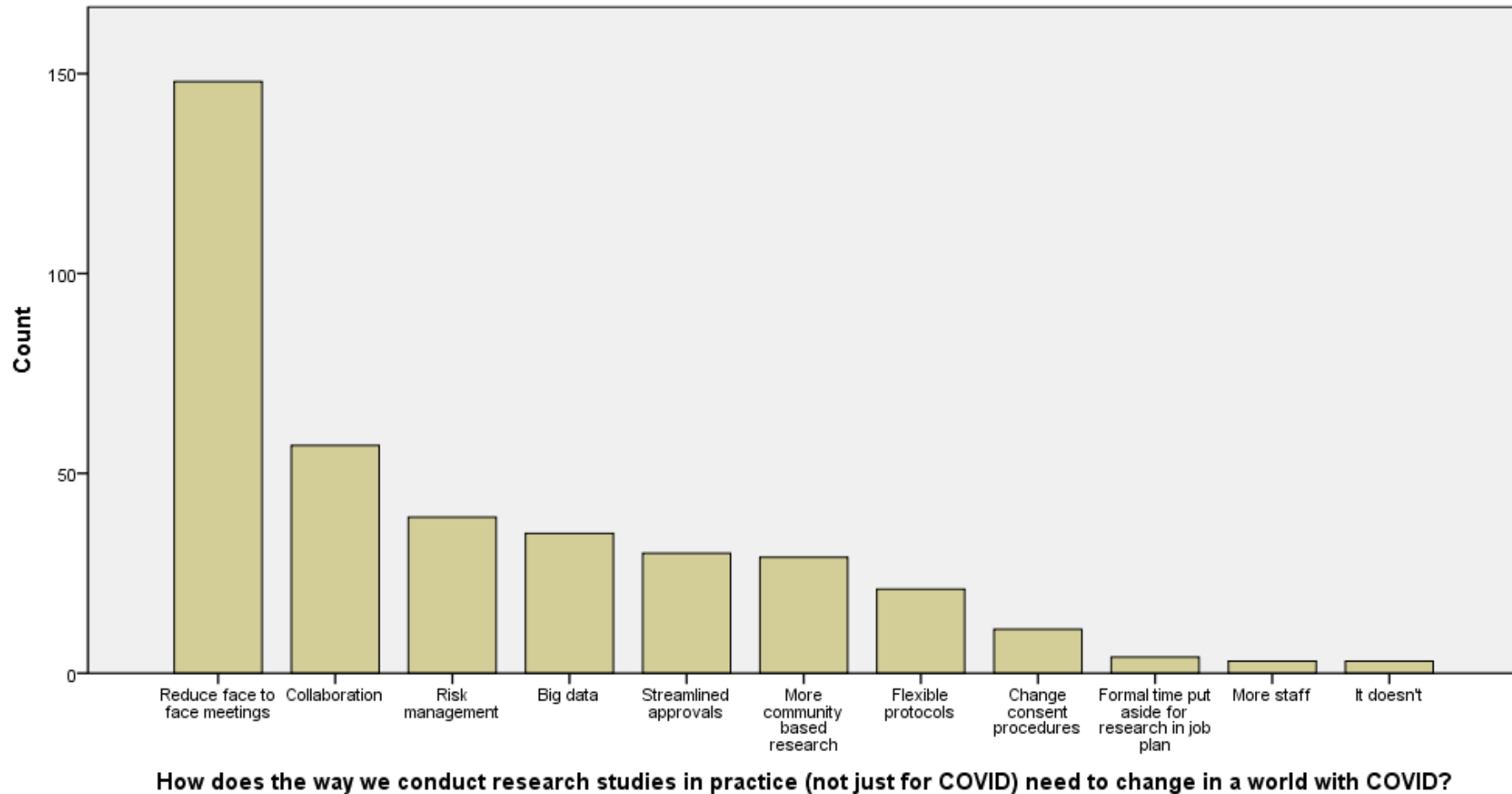




Figure 4. Most popular ways that research delivery needs to change in a world with COVID-19:



## Themes and subthemes

**Table 2. How has the COVID-19 pandemic changed how research for older people is conducted in your organisation?**

1.	Recruitment to non-COVID studies suspended
2.	No face to face contact – e.g. move to remote follow-up, challenges of this new way of working, focus on existing data-sets and using routinely collected data
3.	Focus on COVID research
4.	Positive changes seen – e.g. collaboration, opportunities to contribute to large research studies, accelerated writing and approvals with more streamlined processes, more interest in research, research more inclusive of older people, more interest in care homes
5.	Redeployment of research staff – e.g. clinical academics moved back to clinical work, research nurses pulled back to clinical duties, non-COVID researchers moved to COVID studies
6.	Workforce challenges – e.g. challenges of working from home - “virtual existence”, remote supervision and meetings, conferences and training courses cancelled, freezing of recruitment, threat to career progression
7.	Laboratory based research stopped
8.	No change
9.	Grants/fellowships suspended – e.g. grants and fellowships suspended or cancelled, concerns regarding whether funders will extend studies to allow for the current pause due to COVID
10.	Research seen as lower down the agenda – e.g. clinical staff too busy

**Table 3. Regarding research on COVID-19 and older people, what three areas/topics should be prioritised?**

1.	Management of COVID and its complications – e.g. complications including delirium, coagulopathy, optimal management in intensive care unit (ICU) and non-ICU settings, palliative care, drug trials, patient experience, ethical decision making, rehabilitation post-COVID, supporting staff
2.	Epidemiology – e.g. detailed documentation of presentation, particularly in subgroups including those with dementia, improve recognition and develop screening tools, prognosis including who might benefit from ITU, post-COVID complications and longer term implications including dementia, impact of COVID on frailty/function/quality of life/sarcopenia, additional care needs post infection, accurate data collection methods
3.	Wider societal impact of COVID – e.g. impacts of lockdown on cognition, mental health, mobility, nutrition, mitigating impacts of isolation, supporting carers, elder abuse, optimising health and wellbeing during isolation, challenges specific to certain conditions e.g. dementia
4.	Consequences of the pandemic for other healthcare delivery – e.g. experiences of hospital, novel approaches to providing usual care, access to secondary care, or lack of it, impact of lack of attendance at primary and secondary care, transitions of care – better understanding of and how to improve, challenges of using personal protective equipment, structure of community services
5.	Care home research – e.g. epidemiology, impact on care home staff and residents, sharing knowledge and lessons learned, outbreak management, investment more generally in care home research, perceptions of care homes amongst the general public
6.	Public health interventions – e.g. prevention strategies including vaccine, testing including antibody tests and availability of this, develop a model for optimal care for future pandemics, interventions to promote healthy behaviours, involvement of older people in development of recommendations
7.	Communication in pandemic situations – e.g. with relatives and carers, use of technology - evaluate remote interventions, telemedicine, self management, patient and carer understanding and acceptability of treatment escalation plans and advance care planning, bereavement, impact on death certification and reporting
8.	Pathophysiology of COVID infection in older people – e.g. why are older people more at risk, understand the immune response to COVID and development of immunity, transmission
9.	Research methodology – e.g. patient related outcome measures, inclusion of older people in research, maximum outputs from minimal contact, remote assessments, how to continue research safely, inclusive approaches, inclusion of older people in research priority setting and study design

**Table 4. How do you think the design of research studies for older people (not just for COVID) will need to change in a world with COVID?**

1.	Remote working – e.g. avoid face-to-face contact with participants, reduce need for older people to attend hospitals for follow up, post study drugs, separate hospital sites from research sites, new methods of patient and public involvement, increased use of remote follow up, questionnaires, self reported outcomes
2.	Inclusivity – e.g. no upper age limits, include those who are shielding, lack capacity, live in care homes, all ethnicities, at all stages of studies, from priority setting to design to dissemination, a focus on personal choice around exposure to risk, provide teaching as part of study on how to use the technology, advocating for outcome measures relevant to our cohort, lay summaries for all published studies
3.	Embracing technology and innovation – e.g. to facilitate non face-to-face contact with participants, novel data collection tools, passive devices to monitor participants remotely, particularly for qualitative research, ensuring these do not exclude older population, awareness of limitations of technologies and potential recruitment bias
4.	Infection control – e.g. increased awareness and appreciation of infection control, develop standard operating procedures for environmental cleaning and personal protective equipment in research studies, risk assessments, increased staffing to allow for COVID versus non-COVID workforce, access to testing, flexibility in terms of timing of visits to avoid travelling at peak times
5.	Use of routinely collected data and linkage – e.g. including drive for more observational studies, facilitating delivery of such studies in terms of approvals and access
6.	Efficiency drive – e.g. maximising outputs, reduce number of study visits and length of follow up, large, simpler and pragmatic study designs, pandemic contingency built in to all studies, core outcome sets, improve integration of research into routine care to avoid additional visits to hospital
7.	Pragmatic recruitment – e.g. novel consent process including online
8.	Collaboration – e.g. inclusivity of sites, across disciplines and specialties as well as worldwide, between community and hospitals, social and health care, public health etc, between researchers and stakeholders
9.	Streamlining processes – e.g. from idea conception to study approvals to study set up to recruitment to dissemination and transfer into practice, ensure scrutiny of protocols maintained
10.	Research on hold, stopped or no change
11.	Additional cost – e.g. more time needed for personal protective equipment, more staff required

**Table 5. How does the way we conduct research studies in practice (not just for COVID) need to change in a world with COVID**

1.	Reduce face to face meetings – e.g. remote consultations, use of online/teleconference tools, with research participants as well as amongst study team, virtual conferences, combine research visits with clinical care, streamlining studies, remote outcome measures, empowerment of participants to collect own data, novel data collection strategies
2.	Collaboration – e.g. collaborations with clinicians so that research occurs simultaneously with clinical care, between all care providers, fewer studies, more efficiency, minimum data sets for studies, working with older people to set priorities and relevant outcomes
3.	Risk management – e.g. use of personal protective equipment routine, may involve testing of researchers, more risk assessments
4.	Big data – e.g. use of routinely collected data, easier access, disease registries, sharing data
5.	Streamlined approvals - no less stringent
6.	More community based research – e.g. home visits/ including community recruitment, study households rather than just individuals
7.	Flexible protocols – e.g. contingency for potential further waves – will require more preparation, pragmatism
8.	Change consent procedures – e.g. more remote consent
9.	Formal time set aside for research in job plan – e.g. important as research staff being pulled back to clinical duties, seconding staff to research
10.	More staff
11.	It doesn't

**Table 6. What are the top three lessons you have learned as a result of the impact that COVID-19 has had on research for older people**

1.	Flexibility and resilience – e.g. crisis is opportunity, adapt research ideas and studies to current conditions, be aware of global trends, need to build in flexibility to future studies and alternative plans if further pandemic, streamlining of research – less research but better focused and prepared, alternative consent processes, particularly in those who lack capacity, managing uncertainty
2.	Societal views on ageing and the older population – e.g. ageism remains rife, no geriatricians on any of the influential national organisations advising research or clinical strategy, older people are often excluded but must include them, researchers in this field finding their voices, lack of prioritising care homes, some clinicians do not view ageing research as important, views differ around the world
3.	Collaboration – e.g. galvanised the group, multi-disciplinary team essential, big data really helpful, missed opportunities to learn from existing data due to longstanding issues about access/collation, important to include people with skills regarding research in older people in designing studies, grant applications and studies
4.	We can work virtually/remotely – e.g. importance of technology – upskilling with technology has been achieved, don't actually always need face to face meetings, participants can adapt quickly to virtual interventions, remote consultations can be effective and patients are agreeable
5.	Opportunity to reflect – e.g. why research is important, opportunity to reappraise traditional ways of working, emphasised the gaps in our knowledge regarding biological mechanisms of geriatric syndromes, emphasised lack of care home research, older people are extremely important participants in research, studies during the pandemic have shown that both hospital and community settings can be successful
6.	Research very challenging during a pandemic – e.g. all research has stopped, essential research cannot currently take place, applied health research particularly challenging
7.	Speed – e.g. things can happen quickly when they need to but not at the expense of quality or rigorous ethical review, need for rapid assessment of emerging literature
8.	We work with a vulnerable group – e.g. vulnerable to pandemic, difficult to reach when isolating, may result in greater risk of older people being excluded from studies
9.	Patients still keen to take part – e.g. more interest in research, research with older people is still possible, older people should be included in all research studies
10.	Isolation – e.g. learnt what it feels like, research is very difficult when isolating, older people deteriorate quickly without social interaction, face to face contact invaluable, miss interacting with older people
11.	Clinical work prioritised – e.g. clinical academic posts are vulnerable, research isn't perceived to be important
12.	Resources scarce – e.g. charitable funding vulnerable, research careers vulnerable,

	emphasised lack of resource in older people's medicine to support research, emphasised the chronic lack of funding as no resilience in times of crisis
13.	None/too early to say
14.	Learning points regarding novel methods and tools – e.g. easy to incorporate tools relevant to older people into research but may be completed inaccurately, caution when applying tools designed for older people to younger cohorts e.g. clinical frailty scale
15.	People are scared and need reassurance
16.	Prioritise safety – e.g. protect researchers and participants
17.	More specialists are interested in acute disease in older people
18.	Infectious diseases can still lead to pandemics
19.	Misuse of evidence in policy and politics