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COMMENTARY

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

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Abstract

Older people are disproportionately affected by the COVID-19 pandemic, which has had a profound impact on research as well as clinical service delivery. This commentary identifies key challenges and opportunities in continuing to conduct research with and for older people, both during and after the current pandemic. It shares opinions from responders to an international survey, a range of academic authors and opinions from specialist societies. Priorities in COVID-19 research include its specific presentation in older people, consequences for physical, cognitive and psychological health, treatments and vaccines, rehabilitation, supporting care homes more effectively, the impact of social distancing, lockdown policies and system reconfiguration to provide best health and social care for older people. COVID-19 research needs to be inclusive, particularly involving older people living with frailty, cognitive impairment or multimorbidity, and those living in care homes. Non-COVID-19 related research for older people remains of critical importance and must not be neglected in the rush to study the pandemic. Profound changes are required in the way that we design and deliver research for older people in a world where movement and face-to-face contact are restricted, but we also highlight new opportunities such as the ability to collaborate more widely and to design and deliver research efficiently at scale and speed.

Keywords: COVID-19, pandemic, research, older people

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Key points

- COVID-19 has forced major change in how we do research with older people.
- We outline key priorities for COVID-19 research for older people.
- We discuss how COVID and non-COVID research for older people will need to change.
- Remote assessment, routine data, and rapid collaboration all provide opportunities to improve research in general.

Introduction

The Coronavirus disease 2019 (COVID-19) pandemic has challenged healthcare systems across the world in a way not seen in modern times. Older people are bearing the brunt of the pandemic as a group at the highest risk of hospitalisation and death from COVID-19 illness [1,2], but they are also significantly affected by the loss of social contact, constraints on movement, disrupted supply chains and loss of non-COVID-19 healthcare that are all consequences of the response to the pandemic. Research is a core component of the global response to COVID-19 [3], but the pandemic has had an enormous impact on our ability to design and deliver all research for older people, not just for COVID-19. The aim of this article is to identify what the priority areas are for COVID-19 research for older people, but also to consider how the design and delivery of research for older people will need to change during and after the pandemic. We pool the expertise of an international team of authors, guidance from specialist societies, and results from an international panel of survey respondents engaged in research and clinical care for older people.

Priorities in research for older people in a world with COVID-19

Much of the narrative around research for COVID-19 in the scientific and popular press has focussed on epidemiology, treatment (predominantly drug treatment) and vaccines. As part of the preparation for this commentary, we undertook a survey of researchers and clinicians specialising in the care of older people from the UK, Europe and across the world. The survey aimed to gain their views on priorities for research with older people and lasting impacts on design and delivery of research. Full details of the survey methods and results are given in Supplementary A1. Key priorities identified by the 267 respondents are given in Table 1.

A recent position statement by the British Geriatrics Society highlights some of these areas as key for future research into COVID-19 and older people [4]. A critical missing voice for COVID-19 research for older people is that of older people themselves. We need to know what older people view as priorities, and there is an urgent need to solicit their opinions on this. Such an exercise must be sufficiently inclusive and deliberative to provide robust findings that can underpin research choices over months to years. This could be delivered using existing structures such as the James Lind Alliance, who recently completed a similar exercise setting priorities for research for people living with multiple long-term conditions [5]. In concert, qualitative research on the lived experience of older people with COVID-19, their carers and families, and its wider consequences is needed to complement understanding from epidemiological studies and to underpin the design of interventions.

Making COVID-19 research inclusive

Studies have not always been designed to enable inclusion of people at high risk of the adverse consequences of COVID-19; a third of COVID-19 related trials identified by a recent review had an arbitrary and unjustified upper age cut-off [6], and exclusion criteria for trials too often prevent people with multimorbidity from taking part [7]. Given that the impact of COVID-19 is greatest for older people, it is vital that they are included in such studies. Therefore, studies must be designed to enable safe participation from a broad range of populations, including those living in care homes, and avoid exclusion because of age, multimorbidity or frailty. Including these groups does not come naturally to all clinical specialities or to industry partners, and academics with expertise in research for older people have a key role in collaborating with others to facilitate inclusion of these underserved groups. Such collaboration across multiple specialities is particularly important given the multisystem nature of COVID-19 [8].

Although most trials to date have focussed on hospitalised patients, large platform trials such as the PRINCIPLE trial (Platform randomised trial of interventions against COVID-19 in older people) show that recruitment from community-dwelling populations is possible [9]. However, a focus on place of care or place of residence alone is insufficient; other barriers to participation such as cognitive impairment and lack of capacity need to be addressed and overcome. Some trials have done so successfully by accepting enrolment in best interests in emergency situations, such as is the case for the RECOVERY trial testing treatments in hospitalised patients with COVID-19 [10]. Whilst this is not appropriate for all types of study, the danger to life and function posed by COVID-19 infection to these most vulnerable groups justifies such an approach, with appropriate governance and clinical research expertise.

Technology can improve some aspects of inclusivity, as shown by the ability of videotelephony products to enable housebound individuals, hospital patients and care home residents to stay in touch with their families during the pandemic. However, it also carries risks of disenfranchising some older people, particularly without adequate training. Care is thus needed to ensure that in using technology to improve access to research for some participants, we do

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Table 1. Priorities identified for COVID-19 research for older people (priorities are listed in order from most to least frequently mentioned in survey responses)

Priorities	Examples of themes mentioned
Management of COVID and its complications	Drug treatment trials, managing complications including delirium, end of life care, rehabilitation, outcomes following intensive care unit admission
Epidemiology	Presentation in older subgroups, prognosis, impact on frailty and function, health inequalities, accurate mortality data
Wider societal impact of COVID	Impact of lockdown measures on older people, maintaining mobility, elder abuse, impact on carers
Consequences of the pandemic for other healthcare delivery	Telemedicine and remote delivery of treatment including rehabilitation, impact of postponed investigation and care, access to primary and secondary care, delivering care safely with PPE, experience of hospital care, care delivery models
Care home research	Epidemiology and outcomes in care home residents, impact on care home staff, transmission prevention, end of life care, building capacity for research within care homes
Public health interventions	Vaccines, impact of social distancing on infection, interventions to promote healthy behaviours, access to testing
Communication in pandemic situations	With relatives, use of technology, advance care planning, bereavement, death certification
Pathophysiology of COVID infection in older people	Immune response, transmission, why older people are at higher risk
Research methodology	Inclusion of older people in COVID research, older people's voice in priority setting, patient reported outcomes and remote data collection, how to continue to deliver research safely, how research is publicised and disseminated

not exclude others—particularly older people without the hardware, connectivity, skills, cognition, vision or support to use mobile phones or computers [11]. Maintaining choice in how participants interact with research teams remains important and technology needs to be used as part of a flexible package of communication methods, alongside traditional telephone and face-to-face approaches. Research is needed to understand how best to make these solutions work for the widest range of older people, including those with sensory or cognitive impairment, and existing knowledge needs to be disseminated rapidly to research teams for incorporation into new study designs.

Changes in how we deliver research for older people

Much clinical research has traditionally been conducted via face-to-face contact. However, full or partial lockdowns in many countries in response to the COVID-19 pandemic have exposed the weaknesses of this approach and made it difficult if not impossible to conduct face-to-face research. When face-to-face research does take place, personal protective equipment (PPE) is necessary for participants and research staff, which can impact on communication, as well as on the development of rapport. In the UK, face-to-face research has been drastically scaled back, both to reduce risk to participants and because research staff have been diverted to COVID-19 research or clinical service delivery. Face-to-face follow-up for some clinical trials continues but new recruitment into many studies has stopped, as has face-to-face follow-up of observational studies. These are challenges for traditional models of research participation, but also require changes to how we engage older people in the broader research process. Patient and public involvement and engagement in design, delivery and dissemination is now more important than ever and new processes to enable this in the absence of travel and face-to-face meetings are needed.

Changes to study recruitment

COVID-19 has interrupted many clinical services, particularly non-emergency services. Such services (both in primary and secondary care) often provided the substrate for identifying and recruiting older people into clinical trials. The way that clinical services are delivered is likely to change permanently as a result of the COVID-19 pandemic, with more remote consulting, and a shift in delivery of services via community rather than hospital teams. Traditional methods of finding and recruiting participants, for instance via advertisements and approaches in clinics, cannot take place if older people do not attend healthcare facilities during a pandemic, and will not be fit for purpose if the traditional clinical service model changes to one with a high degree of community contact and remote working. New methods to recruit and consent participants will be needed. These changes provide an opportunity to conduct research differently, reaching participants in different ways and potentially reaching groups who we currently struggle to engage in research. Alternative communication channels, including radio and television advertisements, social media, targeted mailshots and web-based publicity can all contribute to study recruitment, and systems of remote consent (E-consent systems and witnessed telephone or video consent) [12] will also have a role to play. However, it will be just as important to ensure that research forms part of the conversation with a much wider range of healthcare professionals outside the hospital or research institute. Care home staff, community nurses, exercise practitioners and primary care teams all have a role to play in promoting research to older people.

Disease registries have been used with variable success to identify and contact research participants and may provide

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an alternative to clinic or primary care recruitment for some people, particularly if access can be facilitated by carers or family members [13]. However, such registries will only be of use if they include patients with multimorbidity rather than a single, narrowly defined disease. Identification of participants via electronic health records is increasingly used [14], and new technologies such as natural language processing hold out the promise of identifying older people with complex, poorly defined sets of conditions (e.g. frailty, functional impairment) without face to face assessment.

Changes to study assessments and outcomes

Bringing older people to clinic- or hospital-based research appointments is likely to remain difficult in the short-term, due to restrictions on movement, constraints on public transport use, fear of healthcare facilities and strains on healthcare system capacity. Such problems will be magnified in future pandemic waves and highlight the need for a much more robust and flexible portfolio of follow-up mechanisms within clinical studies. Embedding research assessments within routine clinic visits will help to minimise travel and contact with others. Visiting participants in their own homes (with appropriate PPE) may be necessary where study procedures must be conducted face-to-face and travel outside the home is impossible, and physical separation of hospital and research facilities may reassure some participants who are otherwise reluctant to attend. Even these solutions may not work for all groups; stigma associated with visits from staff wearing PPE, and reluctance of care homes to allow researchers to visit are potential barriers.

The COVID-19 pandemic has forced researchers to move to remote follow-up by telephone or video, or to defer or abandon follow-up altogether. Remote follow-up is not possible for all outcomes but such approaches may provide a compromise to enable some follow-up where otherwise none would be possible. Increased use of postal, telephone and video follow-up, posting or delivering study medications to participants, and the use of remote sensing technologies (e.g. accelerometers and other phone/Bluetooth enabled devices) is likely to be necessary. However, such technologies require validation and evaluation in a range of older populations and conditions as a matter of urgency, as exemplified by the work of the EU-funded MOBILISE-D consortium (www.mobilise-d.eu). With the increasing use of electronic healthcare records, it is now possible to use routinely collected clinical data as an additional source of outcomes data, which minimises loss to follow-up and reduces the number of healthcare contacts that an individual needs to undergo. Successful use of such data sources requires that outcomes relevant to research are recorded, and in a reliable and consistent way—the obverse of which is that clinical studies need to select outcomes that are already accurately recorded in routine clinical practice. Where routinely collected data are not fit for purpose (an example being that individuals living in care homes cannot be easily identified from records, or when key outcomes are not measured or recorded in routine data), the COVID-19 pandemic needs to catalyse efforts to improve the range and quality of data held in the electronic patient record.

Research for COVID-19 has also reinforced the value in having agreed, simple sets of core outcome measures focussed on a small number of study questions [15] (such as the WHO ordinal scale for COVID-19 outcomes) [16]; too many studies for older people are dogged by overly complex sets of outcome measures which differ between studies leading to burden on participants and difficulties in pooling data. In parallel with these changes, other study processes including study monitoring, data entry and data verification need to adapt to the constraints of the pandemic; electronic data capture avoids contamination of paper case records, remote monitoring avoids the need for site visits by monitors and the use of electronic health records enables remote data verification without travel or on-site access.

Future-proofing studies

We do not know how many pandemic waves there will be or indeed whether the world will have to live with COVID-19 as an endemic infection with long-term controls on movement of people and healthcare contact. Consequently, research must be robust against future shocks to the healthcare system and to research delivery. This means, wherever possible, significant redesign of existing studies, embedding key principles of flexibility and resilience into future study designs. Changing our delivery mechanisms will ensure that if another pandemic wave hits, research—directly related to COVID-19 but also on all issues relating to health and social care of older people—can still be delivered and will not grind to a halt. In order to make this a reality, much more emphasis will need to be placed on collaborative working and multicentre studies—single centre studies are slow to recruit and vulnerable to local pandemic disruption. Strong links and continuous dialogue with emerging research findings, funders, patients and the public will be necessary to ensure that the research agenda responds quickly to the needs of patients and policymakers as the pandemic progresses.

Opportunities and challenges in non-COVID-19 research

One of the biggest challenges to non-COVID-19 research for older people is currently COVID-19. As discussed, the pandemic has made research hard to conduct in practice, but it has also diverted the time and resources of investigators, funders, regulators and delivery teams away from non-COVID-19 research. No new non-commercial studies were supported for recruitment by the NIHR Clinical Research Network in the UK after 16 March 2020 other than urgent, prioritised COVID-19 studies [17]. Similar data from a survey of the British Association of Stroke Physicians highlighted that the majority of UK stroke research projects had been halted and all responding sites had seen a substantial decrease in stroke research activity. The economic shock delivered by the pandemic is likely to lead

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to significant cuts to public and charity budgets across the world, and it is unclear to what extent this will affect medical research [18]. Even if medical research budgets are preserved, COVID-19-related research is now likely to compete with non-COVID-19 research.

The key lesson to be learned from successful COVID-19 research is that doing fewer studies at larger scale pays dividends—duplication is reduced, participants can be recruited and data collected at speed, and results are more robust. The COVID-19 pandemic has shone a harsh light on the wasted effort and opportunity in conducting small or poorly designed studies, which have had a disproportionate and often adverse impact on public discourse and policymaking [19]. Successful international collaborations [20] have enabled rapid learning from cross-country comparisons. These lessons remain relevant to all research for older people.

Wise funders and researchers will need to find ways to combine the study of COVID-19 with important non-COVID-19 research priorities, ensuring that we continue to improve diagnosis and treatment of frailty, sarcopenia, bone health, dementia, delirium, stroke, movement disorders, incontinence and the other myriad conditions that affect older people. The COVID-19 pandemic has brought the concept of frailty to a much wider audience, and the pandemic has also highlighted the needs of the care home sector and the importance of mental health in older people. These are opportunities to be capitalised upon, and it is essential that researchers continue to focus on a broad range of conditions of importance; skewing the research agenda towards COVID-19 at the expense of these other conditions does a disservice to our patients. The pivotal role of discovery science and experimental medicine in the COVID-19 response should also stimulate clinical researchers to work more closely with our preclinical colleagues—the answers to diseases of ageing lie in translating insights from the laboratory through into clinical research at much greater speed and volume than has been the case until now.

The interruption to normal clinical and research activity is a challenge to our research workforce. Established practitioners may need to drastically change their approach to research focus, design and delivery, taking many out of their comfort zone and adding stress to a research culture that is already heavily performance-driven. Conversely, the pandemic response gives the academic community an opportunity to refocus on what is really important in research, rather than the current narrow set of performance measures. Supporting emerging researchers in a time of uncertainty will also be essential [21]; clinical academic trainees including nursing and allied health professions colleagues have paused research to return to clinical duties and many non-COVID clinical and laboratory projects have been paused. The pandemic risks disrupting career progression which depends on project completion, obtaining grants or fellowships; a flexible approach to assessing career milestones, research degree progress and fellowship applications should be applied by funders.

History teaches us that all periods of disruption bring benefits as well as setbacks and it is important to reflect on the gains that the research community will have made during this pandemic. We are finding new ways to work, building new collaborations and benefitting from cross-fertilisation of ideas and techniques as we learn at speed from colleagues; it is heartening to see plans for a European Geriatric Medicine Society virtual conference dedicated to COVID-19 for just these purposes [22]. This learning, if properly used, will enhance research for older people, and we have a duty to ensure that these benefits deliver faster, better research for older people both during the pandemic and in the years to come.

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