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RESEARCH PAPER

Inclusion of older adults in UK clinical research—the National Institute for Health and Care Research Year of Birth Project

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Abstract

Introduction: Inclusion of older adults in research ensures both equity and relevance. We used National Institute of Health and Care Research Year of Birth data to describe inclusion of older adults in contemporary UK clinical research.
Methods: We worked with English research networks to collect individual participant level data on recruits into National Institute of Health and Care Research portfolio studies. We used data from 2022–2023 to 2023–2024 to assess participation. We described data in terms of geography, primary speciality managing the study and study characteristics. In subgroup analyses, we assessed inclusion of the 'oldest old' (aged over 85 years) and inclusion in research from three exemplars: heart failure, Parkinson's disease and palliative care.
Results: In total, 455 734 participants were included in the analyses. The most common age group included in UK research was 65–74 years (15.5%). People aged over 85 years were 3.2% of all recruits, and this proportion decreased over time. There was modest geographical variation in participant age but marked variation by recruiting speciality. People aged over 85 years accounted for less than 5% of the total participants recruited in 9 of 14 specialities assessed. Older adults were less likely to be recruited into commercial studies. For three conditions of interest, recruitment did not match population epidemiology.
Conclusion: This project has demonstrated feasibility of collecting participant age data at scale and provides important metrics for understanding study participation. While there is scope to improve older adult participation across all the study portfolio, there are major equity issues around inclusion in certain speciality areas and commercial research. *To complement this abstract, a video abstract is available online*.

Keywords: inclusion; older adults; research; trials

Key points

- It is feasible to collect data on the age of clinical research participants at national scale.
- Inclusion of older adults (aged over 85 years) is uncommon, and decreasing, in UK clinical research.
- There is variation in the inclusion of older adults by geography, study sponsor, and clinical speciality.
- The National Institute of Health and Care Research Year of Birth data can be used to track progress against the national priority of increasing the numbers of older adults participating in clinical research.

Introduction

For a clinical study to have real-world relevance, the profile of the study population needs to be as close as possible to the intended patient population. However, this is often not the case [1, 2]. There are many instances of treatments, studied almost exclusively in one subset of the population, that are later shown not to have equivalent effectiveness in other, sometimes larger, patient groups. Examples include ethnic difference in ischaemic heart disease prevention and blood pressure control strategies [3, 4].

A group that has been historically under-represented in healthcare research are older adults [5]. This means that geriatric medicine as a speciality has one of the worst ratios of clinical trial evidence to patient numbers. This evidence-practice disconnect is a substantial missed opportunity. The majority of the hospital inpatient population, and a high proportion of health and social care expenditure are related to older adults [6]. At worst, this represents inherent ageism in clinical research and will lead to clinical practice recommendations that are not relevant to the main consumers of health care [7].

It is recognised that recruiting older adults, especially older adults living with frailty, to clinical research studies is challenging. There are many potential barriers to inclusion of this group, including, but not limited to, physical and cognitive impairments, multiple long-term conditions and reduced healthcare literacy. These practical difficulties of recruitment can be compounded by study protocols that set arbitrary upper age thresholds for inclusion, or stipulate other criteria that will exclude the majority of older adults [8].

However, recruitment of older adults into multi-centre clinical trials is possible, with recent high profile examples [9, 10], and supporting guidance from international societies [11]. The landscape is changing, and in the UK, best practice around the inclusion of older adults in research has been published [12], the Chief Medical Officer has issued an annual report themed around older adults with recommendations for greater research inclusion [13], and a recent 'statement of intent' signed by major UK research funders has underlined a commitment to increasing older adult participation in research [14].

To fully understand the inclusion of older adults in research, to allow us to audit practice and to monitor temporal trends, we need access to timely, robust, data on the ages of research participants at national scale. While most studies report average age as part of baseline demographics, more granular data on the ages of participants are often lacking [15]. In the UK, a large proportion of clinical research studies are eligible to register with the National Institutes of Health and Care Research (NIHR) Research Delivery Network (RDN) (formerly the Clinical Research Network (CRN)) portfolio service [16]. NIHR portfolio inclusion brings many benefits to investigators, but also comes with a requirement for mandatory reporting at the level of the person recruited. Although numbers of participants recruited is routinely reported by local sites via the RDN Central Portfolio Management System, no national data on participant characteristics was traditionally collated. To improve inclusivity and equity in research participation, in 2021 a system to allow routine capture of research participants' year of birth (YoB) was introduced, as a first step towards building a national dataset on research demographics.

Here, we present initial data from this NIHR's YoB project, exploring the data through the lens of inclusion of older adults. Our specific aims were to describe patterns of age for participants in UK clinical research by discipline speciality, by geography and by study type.

Material and methods

Data collection

Full details of the methods underpinning the NIHR YoB project have been described previously [17]. In brief, the original NIHR YoB pilot was designed to assess the feasibility of collecting participants' age through existing local systems and to use these data to understand the scale, variation and challenges of individual participant data collection across England. From 2021, the NIHR CRN Coordinating Centre collaborated with the 15 Local Clinical Research Networks (LCRNs) in England to implement data collection. NHS Trusts were asked to report the YoB of participants via their Local Portfolio Management Systems.

Data selection and categorisation

We limited analyses to data from years 2022–2023 to 2023–2024. Choosing these as years with most complete data availability, and less likely to be impacted by COVID-19 healthcare restrictions.

Deriving age from YoB, we linked these data to other data routinely captured as part of national mandatory reporting. We created classifications to divide the data according to key variables of interest.

Age ranges

We pre-specified age ranges of greater than 65 years (an age commonly used to define eligibility for retirement) and age greater than 85 years (an age commonly considered as 'oldest old'), with a middle threshold of 75 years (recognising the potential heterogeneity in the group 65–85 years old) [18].

Clinical speciality

We used the speciality definitions of the NIHR CRN, including the speciality of 'ageing', but excluding 'children' and 'reproductive health'. We noted where a speciality 'managed' a portfolio study, i.e. were primarily responsible for the successful delivery of the study; and where a speciality 'supported' a study, i.e. assisted another speciality who were managing the study.

Geography

We used the 15 regions of England that defined the NIHR LCRNs.

Study type

We categorised research as clinical trials of an investigational medicinal product (CTIMP i.e. a 'drug trial') and non-CTIMP. We also categorised as 'commercial' (where a company was the primary sponsor) and 'non-commercial' (where a hospital, university or individual investigator was the sponsor).

Exemplar conditions

We choose two conditions, and one healthcare context, where relevant patients were likely to be older adults, but that did not traditionally fall under the NIHR CRN 'ageing' classification, these were: heart failure, Parkinson's disease and palliative care studies. These conditions were defined using ICD 10 diagnostic codes and speciality codes. We compared patterns of recruitment with UK data on population prevalence by age [19–21].

Analyses

We used descriptive statistics, reporting absolute numbers and proportions for our three chosen age bands and by classifications outlined above. Where appropriate, means and proportions were assessed using relevant comparative analyses. We created tables and data visualisations. All descriptive analyses were performed using *IBM SPSS* version 29.0.1.0 software. We created a map comparing proportions of older adults in research and proportions of older adults in the region, using UK census data. This work was fully supported by the NIHR, with no external support. Data were fully anonymous and no additional ethical approvals were required for these analyses.

Results

In the 4 years since inception, the NIHR YoB project has collected age data for over 1 million participants, with numbers increasing. These people were recruited to over 4900 portfolio studies, across 204 NHS Trusts in England. The average age of NIHR portfolio study participants was 48.4 years, with the most common 10-year age band being those aged 65–74 years, accounting for 15.5% of total UK research participants.

Not all portfolio studies or regions consistently reported YoB data and regional responses varied across the study period. Although overall, the number of studies reporting YOB data increased across the two years from 7343 to 8171 studies.

During the period 2022–2023, 207 490 participants were included in research reporting YoB data, of which 85 945 (41%) were aged over 65 years and 10 726 (5%) aged over 85 years. Equivalent figures for 2023–2024 were 248 244 participants, 95 399 (38%) over 65 years old and 11 401 (4.5%) over 85 years old, a decrease in older adult recruitment ($P < .0001$). Across the relevant portfolio, 4145/5608 (74%) of studies recruited any participants aged over 65 years.

Table 1 describes recruitment by selected NIHR CRN/RDN speciality group for each of our pre-specified age bands. Compared to other RDN/CRN disciplines, recruitment to those studies managed by the ageing speciality was modest. Other than for those studies primarily managed by the ageing speciality group, there was a general pattern of lower proportional recruitment with increasing age. As a proportion of total recruitment, recruitment of the 'oldest old' (those aged over 85 years) was single figures for all specialities except ageing, respiratory, stroke and trauma. Low proportional recruitment of this age group was seen for many specialties where older adults would be a major service user group, e.g. cancer, dementia and mental health.

Table 2 presents recruitment by age band, categorised by geography, using the NIHR clinical research network sites, Figure 1 compares research participation by age in RDN regions. There is variation in recruitment of older adults by region. There was no clear relationship between overall research study activity (number of portfolio studies in the region) and inclusion of older adults.

Table 3 presents recruitment by age band, categorised by study type. Overall, 3579 CTIMP and 2744 non-CTIMP studies reported YOB data in our period of interest. There was no difference in proportions of trials recruiting older adults. However, comparing commercial and non-commercial studies, those aged >85 years were better represented in non-commercial trials to commercial trials (3.5% vs. 2.4%, $P < .001$).

Table 4 presents recruitment by age band for three exemplar conditions and highlights age related decreases in study participation and an overall disproportionately small representation of older adults compared to the community epidemiology of the chosen conditions.

Table 1. Age based recruitment by study managing speciality.

Speciality	No. of studies with relevant data/no. of studies 4145/5608	2022–2023 (number and proportion of total recruitment)			2023–2034 (number and proportion of total recruitment)		
		65–75	76–85	>85	65–75	76–85	>85
Ageing	20/21	166	259	158	287	753	783
	19/20	23.9%	37.3%	22.7%	14.6%	38.5%	40%
Anaesthesia pain and	30/43	3019	2324	526	4240	2747	476
perioperative	35/45	27.5%	21.2%	4.8%	24%	15.5%	2.6%
Cancer	598/757	7663	3767	572	10,618	4716	627
	641/787	27.2%	13.3%	2%	53.2%	23.6%	3.1%
Cardiovascular	197/227	5132	4275	1093	3907	3861	1128
	205/238	29.4%	24.5%	6.2%	26.2%	25.7%	7.5%
Dementia and	132/120	1582	1222	329	1876	1637	298
neurodegeneration	140/160	30.7%	23.7%	6.3%	31.3%	32,3%	4.9%
Diabetes	43/64	1065	515	79	1073	527	94
	49/73	17.3%	8.4%	1.2%	18.4%	9%	1.6%
Gastroenterology	81/109	3824	1902	217	3996	2086	228
	75/104	19.6%	12.6%	1.4%	22.1%	11.5%	1.2%
Infection	58/104	1590	481	209	1228	551	185
	56/103	14.9%	4.5%	1.9%	17.5%	7.8%	2.6%
Mental health	35/131	184	66	13	416	146	32
	48/146	4.1%	1.4%	0.2%	3.7%	1.3%	0.2%
Musculoskeletal and	129/178	2505	1357	225	2929	1614	217
orthopaedics	144/191	24.1%	13%	2.1%	22.7%	12.5%	1.7%
Neurology	55/97	2347	1674	456	1519	1237	327
	55/101	19.5%	13.9%	3.7%	17.1%	13.9%	3.6%
Respiratory	112/134	4345	4188	3071	4615	4378	2670
	117/144	22.1%	21.3%	15.6%	23.9%	22.7%	13.8%
Stroke	53/58	894	1068	476	1022	1254	809
	60/64	23.2%	27.8%	12.4%	22%	27%	17.4%
Trauma and emergency	64/76	2160	2395	1648	2427	2490	1454
care	52/62	15.3%	16.9%	11.6%	17.6%	18.1%	9.8%

Table contains a selection of the NIHR clinical research network specialities.

Discussion

Improving the inclusion of older adults in clinical research is recognised as a priority in the UK [13]. The NIHR YoB project demonstrates encouraging recruitment of those over retirement age, but there is still considerable work to be done, as recruitment of the oldest old remains only a fraction of total UK research activity. Concerningly, as a proportion of total recruitment, older adult participation is decreasing over time, and recruitment patterns are not always representative of the real-world distribution of disease.

Comparing study recruitment to UK census data helps contextualise the YoB data. In the last census, people aged over 65 comprised 19% of the UK population, while those aged over 85 years comprised 2.4% [22]. These percentages compare favourably to the total proportional recruits by age band. However, if we consider the UK population with medical conditions requiring intervention (the primary focus of clinical research), this population are predominantly older adults, confirming the need to improve participation of this group [23]. To assess research participation age against population age, we choose three exemplar conditions, namely heart failure, Parkinson's disease and palliative care. For heart failure, the majority of UK disease is in those aged over 75 years, with mean age of diagnosis 79 for women [19]. However, in the YoB data, participants recruited were much younger. Similar disconnects between recruitment and UK prevalence patterns were seen for Parkinson's disease (where peak diagnosis is in those aged over 80 years) [20] and for people requiring palliative care (where the median age of requiring this input is 75 years) [21].

A recognition of the under inclusion of older adults in clinical research is not new. A 2020 paper used condition-specific estimates of research recruitment in diabetes, cardiology and cancer studies to illustrate the paucity of older adults in research [24]. That review noted that a major diabetes trial that informed guidelines had an average age of only 53 years, a meta-review of oncology studies showed less than a third of eligible older adults were recruited to trials [25] and less than a quarter of older Medicare beneficiaries with heart failure met enrolment criteria landmark heart failure studies [26]. While there has been progress made, e.g. the NIHR INCLUDE guidance [12], there is clearly still substantial work to be done. Internationally, this feeling of a journey started, but far from completed, is recognised by those working to improve older adults' inclusion in US research [27].

Table 2. Age-based recruitment across NIHR clinical research network regions in England.

Region	No. of studies with relevant data/no. of studies	2022–2023 (number and proportion of total recruitment)			2023–2024 (number and proportion of total recruitment)		
		65–75	76–85	>85	65–75	76–85	>85
East Midland	179/255	1314	894	233	1724	1370	684
	187/272	(15.8%)	(10.5%)	(2.7%)	(13.6%)	(10.8%)	(5.4%)
East of England	240/328	2112	1636	383	1863	1516	371
	228/314	(17.7%)	(13.7%)	(3.2%)	(13.8%)	(11.2%)	(2.7%)
Greater Manchester	97/143	1569	1091	226	5397	2542	707
	331/522	(17.4%)	(12.1%)	(2.5%)	(15.9%)	(7.5%)	(2%)
Kent Surrey and Sussex	190/281	1979	1877	753	2127	2046	520
	198/294	(16.6%)	(15.7%)	(6.3%)	(15.3%)	(14.7%)	(3.7%)
North East and North	480/752	4824	2880	797	4883	3269	1034
Cumbria	477/734	(14.7%)	(8.7%)	(2.4%)	(12.8%)	(8.5%)	(2.7%)
North Thames	301/517	2861	2190	709	3885	2802	679
	426/698	(19.3%)	(14.7%)	(4.7%)	(12.4%)	(8.9%)	(2.1)
North West Coast	337/543	3011	1971	459	3159	2061	495
	347/559	(15.3%)	(10%)	(2.2%)	(13.3%)	(8.6%)	(2%)
North West London	254/437	1442	928	355	1718	1150	475
	270/475	(9.5%)	(6.1%)	(2.3%)	(12.9%)	(8.6%)	(3.5%)
South London	400/670	2216	1408	298	2815	1839	556
	497/823	(18.8%)	(11.9%)	(2.5%)	(15.1%)	(9.8%)	(2.9%)
South West Peninsula	346/465	2641	1912	428	2343	1710	388
	353/459	(20.4%)	(14.8%)	(3.2%)	(23.5%)	(17.1%)	(3.9%)
Thames Valley and South	266/422	1461	1033	288	1902	1666	565
Midlands	324/496	(8.3%)	(5.8%)	(1.6%)	(7.5%)	(6.6%)	(2.2%)
West of England	271/430	4713	4585	3278	4328	4101	2660
	278/440	(17%)	(16.5%)	(11.8%)	(17.3%)	(16.3%)	(10.6%)
Wessex	352/528	3651	2700	811	3052	2246	566
	325/496	(21.5%)	(15.9%)	(4.7%)	(20.2%)	(14.9%)	(3.7%)
West Midlands	443/756	3789	2502	672	3444	2778	722
	443/739	(17.5%)	(11.5%)	(3.1%)	(15.7%)	(12.7%)	(3.3%)
Yorkshire and Humber	513/816	6496	3609	1065	6419	3975	996
	558/850	(16.2%)	(9%)	(2.6%)	(11.7%)	(7.2%)	(1.8%)

Table 3. Age-based recruitment by study type.

Study type 9911/15514	No. of studies with relevant data/no. of studies	2022–2023 (number and proportion of total recruitment)			2023–2034 m (number and proportion of total recruitment)		
		65–75	76–85	>85	65–75	76–85	>85
ALL portfolio	4669/7343	44,079	31,216	10,755	49,059	35,071	11,418
	5242/8171	(15.8%)	(11.2%)	(3.8%)	(14%)	(10%)	(3.2%)
Ageing managed	20/4669	166	259	158	347	792	790
	21/5242	(23.9%)	(37.3%)	(22.7%)	(17.8%)	(38.4%)	(38.3%)
Ageing supported	56/4669	909	1409	666	1237	1105	562
	60/5242	(24.5%)	(37.9%)	(17.9%)	(34.5%)	(30.8%)	(915.6%)
CTIMP	1122/1748	17,372	11,504	3554	19,936	15,201	5360
	1200/1831	(16.3%)	(10.3%)	(3.3%)	(14.4%)	(10.9%)	(3.8%)
Non CTIMP	920/1359	26,707	19,712	7201	29,123	19,870	6058
	939/1385	(15.5%)	(11.5%)	(4.2%)	(13.7%)	(9.3%)	(2.8%)
Commercial	525/864	3364	1868	400	3526	2238	431
	603/940	(21.1%)	(11.7%)	(2.5%)	(19.6%)	(12.4%)	(2.4%)
Non-commercial	1517/2243	40,715	29,348	10,355	45,533	32,833	10,987
	1536/2276	(15.5%)	(7.7%)	(3.9%)	(13.6%)	(9.8%)	(3.3%)

CTIMP, Clinical Trial of an Investigational Medicinal Product.

Increasing older adult participation in research requires not only an increase in studies with a focus on syndromes of older age, but also increasing older adult participation across all studies. Older adults are commonly affected by a variety of organ specific conditions, and if recruitment to studies mirrored the natural epidemiology of these conditions, we

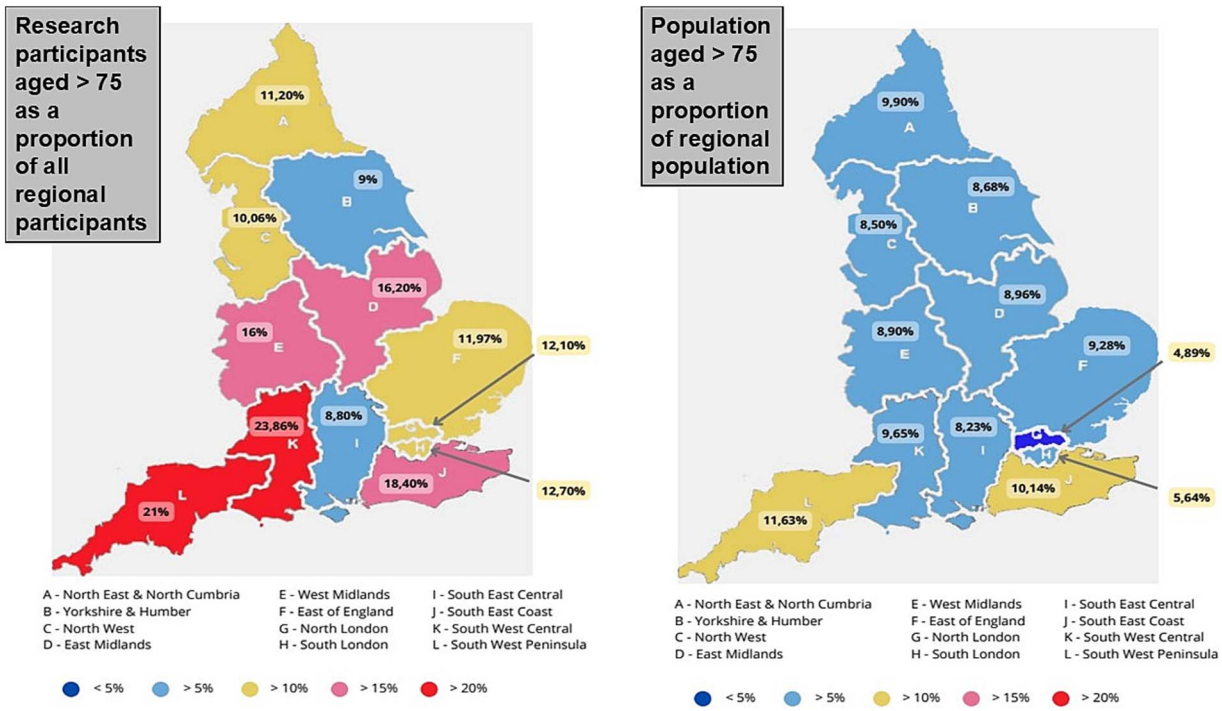

Figure 1. Research participants aged over 75 years as a proportion of all research participants by region, people aged over 75 as a proportion of the regional population. The regions are presented as NIHR Research Delivery Network Regions.

Table 4. Age-based recruitment for three exemplar conditions of older age.

Disease area	Managed speciality	No. of studies with data/no. of studies	2022–2023 (number and proportion of total recruitment)			2023–2034 (number and proportion of total recruitment)		
			65–75	76–85	>85	65–75	76–85	>85
Heart failure	UK prevalence		2.9%	6.7%	14.3%	2.9%	6.7%	14.3%
	CV	69/74	1191	871	179	1257	1021	256
		71/80	(28.2%)	(20.6%)	(4.2%)	(27.5%)	(22.3%)	(5.6%)
	Other	9/12	60	53	19	84	42	11
		8/9	(18.9%)	(16.7%)	(6%)	(26.2%)	(13.1%)	(3.4%)
Parkinson's	UK prevalence		1.0%	1.4%	1.6%	1.0%	1.4%	1.6%
	Neuro	45/45	832	324	33	908	542	88
		46/49	(44.3%)	(17.2%)	(1.7%)	(37.3%)	(22.2%)	(3.6%)
	Other	7/7	208	153	25	295	160	24
		11/11	(20%)	(14.7%)	(2.4%)	(16.5%)	(8.9%)	(1.3%)
Palliative care	Median age of death in UK palliative care: 74 years							
	Palliative	19/22	319	237	54	510	413	112
		19/22	(26.9%)	(20%)	(4.5%)	(30%)	(24.3%)	(6.5%)
	Other	4/9	46	44	18	72	47	4
		4/8	(13.1%)	(12.6%)	(5.1%)	(12.5%)	(8.1%)	(0.6%)

would not see patterns of low older adult participation in research with a focus on cancer, dementia and neurodegenerative diseases. Exploring the variation in inclusion of older adults can suggest targets for intervention, e.g. working with commercial sponsors to increase proportions of the oldest old in their trials or selecting conditions where inclusion of this demographic is lower than expected. Specific disease areas such as neurology and cancer have described challenges and solutions to improving research inclusion [28, 29]. The progress made in these areas gives us encouragement to work harder on improving access to research for older adults.

Our work complements a recent project completed by the UK research funder The Vivensa Foundation [30]. They described the UK Ageing research ecosystem and reported that most UK ageing research was funded by public sector (e.g. NIHR). The report recognised age-based disparities beyond inclusion, with research need (availability of evidence versus associated disability adjusted life years) not

matching available funding, and majority of ageing-related research being concentrated in London and the South-East England. While these are areas of world leading academic activity, they are not the areas of the UK with the highest prevalence of older adults or frailty. In our analysis comparing regional population ages with ages of those included in research, there is marked regional heterogeneity. Those areas with the largest number of older people, have the highest recruitment of older adults into research, but the regional differences are modest, and it would be wrong to state that UK NIHR study participation perfectly matches population ageing patterns.

Accurate, real-time data on characteristics of participants in research offer a powerful resource to ensure the community are working towards equity and external validity of clinical research. The granularity afforded by individual participant-level data allow for assessment of temporal trends, subgroups and comparisons across regions or disciplines. Continued reporting of YoB will provide a benchmark to measure progress in older adult inclusion at local, national and international level—and may encourage other countries to report similar data.

The YoB data have potential applications from local audit through to guiding national policy. Mapping regional variation in inclusion of older adults, allows both peer-to-peer geographical comparisons, and comparisons within a region, checking recruitment against regional demographics. Certain UK research regions have higher proportions of older adult residents, and we aware that Ageing specialty teams within some of these regions are starting to use the YoB data to guide local research recruitment decisions. At a national level, the data permit UK policy makers to closely examine the impact of interventions such as themed calls for older adult research, and the promotion of inclusion-based study paradigms.

The YoB data offer granular information on age of research participants from across the UK. Despite its many opportunities, there are limitations to the current data. Those working in older adult research will be aware that chronological age is a blunt tool for describing biological age, or the common syndromes associated with older age such as frailty [31]. However, as an objective, easy to collect variable, chronological age may serve as a suitable proxy for use at scale.

Missing data are always an issue with data collection at national scale, and contributing data to the YoB project was not mandatory for trusts or studies. There is potential for biases in the missing data, e.g. those with better inclusion of older adults may be more likely to submit data, and as data are predominantly from secondary care, may not be generalisable to other settings e.g. care-homes or primary care. However, it seems unlikely that the non-participating sites and studies have substantially better inclusion than those that submitted data.

The YoB project has demonstrated feasibility of collecting participant age data at scale across the NIHR portfolio and aids our understanding of who takes part in research and where gaps remain. However, to fully assess equity, other demographic data (such as ethnicity, gender and socioeconomic status) must also be monitored. In this regard, the UK Department of Health and Social Care is piloting a scheme to collate more granular demographic information of research participants, including sex and socioeconomic deprivation. Specific to older adult research, there would be a desire to complement the protected characteristic of age, with data on frailty, and multiple long-term conditions. Achieving this will require negotiating issues around data governance and inter-operability of data sources. These developments in data monitoring are essential if we wish to realise the ambition of making research more inclusive, representative and aligned to population health needs.

'If you cannot measure it, you can not improve it'. To have reached, a point at which YoB recording is encouraged for all studies on the NIHR portfolio is a major milestone towards a goal of improving the inclusion of older adults in research. The current YoB data show the importance of older adults in UK clinical research but also highlights variation and opportunities to improve participation in particular specialities, localities and study types.

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Supplementary Data: Supplementary data is available at *Age and Ageing* online.

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