Long-term care challenges in the 2020s

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Preface

The Care Initiative was set up in Green Templeton College in 2013 by several college fellows led by Mary Daly, Governing Body Fellow and Professor of Sociology and Social Policy at the Department of Social Policy and Intervention. Its mission is to be a forum in Oxford that, through informed debate and research, advances and shares knowledge about the complex issues involved in the care of older persons.

The challenges of caring for ageing persons in an increasingly ageing society are diverse and multi-faceted, and benefit from analysis from a range of disciplinary and professional perspectives. Viewing care as a societal and economic challenge, the Initiative's approach is to consider the issues relating to care from multiple vantage points, and to attend to its resource, ethical and policy/service dimensions from both academic and praxis perspectives. Key topics that the Initiative has focused on include: investments in and costs of social care; innovations in social and health care (with particular reference to online and digital, technological innovations); reimagining and remodelling care; philosophies of care and caring; and the degree to which physical, social and personal environments enable people to live out their lives in the place(s) which they consider home.

The Initiative has been funded and supported by Green Templeton since its inception. Its mission is rooted in the college's engagement with, and commitment, to human welfare as a foundational college interest and common concern. The Initiative's membership also reflects the diverse disciplinary orientations of the College, drawing together scholars and students especially from medical sciences, social sciences, and business and management programmes at Oxford. Since its formal launch in October 2014 through a lecture by Sir Andrew Dilnot, Chair of the Commission on Funding of Care and Support, its main activities have been lectures and panel discussions ('Conversations on Care'). These events have been designed to appeal both to people in the public service and charity sectors, and to academics in Oxford and elsewhere. In this it has been very successful, having assembled a wide community of interest through these activities.

As part of its efforts to plan for its future, in early 2024 the Care Initiative hired Dr Kate Murnane as a postdoctoral researcher and conduct background research to inform the planning process. Dr Murnane completed her DPhil in Medical Sciences at Oxford, and is currently completing her graduate-entry medical studies at Oxford. In this report, Dr Murnane reviews the thinking and latest research on a range of challenges to the social care landscape. An accompanying report, co-authored by Professor Daly and Dr Murnane, identifies and discusses possible areas on which the Initiative might focus its future efforts.

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0. Introduction

0.1 Scope and Aims

This report reviews and assesses the state of knowledge in relation to four major issues: (i) the use of technology in social care; (ii) workforce issues in social care; (iii) informal care; and (iv) the development of a care infrastructure in the Global South. These issues were initially identified through general searches of research and policy evidence. They are reviewed especially for their feasibility as potential foci for the Care Initiative in Green Templeton College, University of Oxford. In outlining each theme, the intent is to identify emerging issues which reflect the challenges and opportunities in each domain. A set of key questions is presented in a concluding section.

0.2 Methodology

The review was undertaken over six weeks, using predominantly google searches, examining member-affiliate directories of Care England and Help Age International UK (Age International), and field-specific academic journals such as [the] *International Journal of Integrated Care* and *The Journal of Long-Term Care*, accessed via PubMed. A wide range of literature was surveyed, from primary social care research and social policy reports and legislation to political essays and blogs and other pieces oriented to public discussion. Local, national and international activities were scrutinised. The information reported is valid as of mid-2024.
The focus is on adult social care which is a broad term and one frequently used in a loose fashion. For the purposes of this review, the following definition used by the King's Fund was adopted: "Adult social care pertains to a wide range of activities to help people who are older or living with disability or physical or mental illness live independently and stay well and safe" (The Kings Fund, 2023). The demographic group of most interest for the Care Initiative, and hence this review, is older adults whose care may be delivered in the home, nursing/care homes and hospital settings. Because of relatively limited resources, the short time period and the often-local nature of some activities, the information should be interpreted as indicating the main activity in the field, rather than as representing a full and comprehensive survey of what exists. The focus on England within the national context should also be noted.

1. Technology in Social Care

Technological developments – especially artificial intelligence (AI) – are often feared because of the perceived threat that they represent, such as their potential to displace human beings from paid employment. Recent polling of EU member states via the Eurobarometer indicated that perceived threat of job loss and inefficacy were leading public concerns about increased implementation of AI (Shoss and Ciarlante, 2022). Yet these developments may also present opportunities to significantly enhance aspects of human life and activity. This is as true of social care provision as it is of other domains. Projection analyses by the Department for Business, Energy & Industrial Strategy (BEIS) indicates that "the largest net employment gains [due to AI implementation] over the next 20 years may be seen in the health and social care sector, building up steadily over time" (BEIS, 2021, pg. 26) with the caveat that much of the net positive employment effect for these hard-to-automate sectors is likely to be additional job creation. However, this work also found that AI implementation may exacerbate regional employment and workplace inequalities. In other

words, a more positive net impact (job creation, upskilling and career development) is anticipated in regions with greater baseline median earnings compared with poorer regions where automation is predicted to have a negative employment effect in the sense of replacing jobs (BEIS, 2021).

Turning to policy, one of the stated aims in *People at the Heart of Care* – the policy plan for adult social care in place at the time of writing – is for UK carers to have 'the confidence to use technology that supports people's needs and frees up time to deliver outstanding care' (DHSC, 2021).

A recent review by the Kings Fund (Maguire et al, 2021) indicates that current applications of technology in health and social care typically include AI, mobile computing, wearable technology, and the internet of things. Much of the pilot research evaluating assistive technologies has been undertaken in health care and medical settings, with a pattern of some applicable and promising interventions then transitioned into the social care sector.

Until the last decade, most of the developments and applications of technology in medical and healthcare settings centred on internet-based interfaces and mobile computing. Key examples include digitising patient records on centralised electronic platforms, utilising prioritisation and screening tools when triaging emergency admissions, and using telemedicine platforms for remote diagnoses and treatment planning. Over the last decade, there has been increased investment in wearable technologies, most notably for monitoring day-to-day cardiac health, and for tracking measures that include glucose levels in diabetes management and falls in prone populations. Computational models have also increasingly been deployed, such as to model flow through emergency services in hospital setting in order to evaluate different triage approaches (King et al, 2022; Townsend et al, 2023). At the same time, AI has become a major target for investment and is expected to have a large impact on care delivery in the future (Hamblin, 2020; Litchfield et al, 2023).

The COVID-19 pandemic exerted a significant impact on tech-related progress and discussions in regard to both health and social care. In many ways, the pandemic accelerated integration of technology into day-to-day practice, with mixed results. It also facilitated (unplanned) studies of distanced and virtual care. Some of the success stories in healthcare included virtual wards (Warton and Fulop, 2022; Hakim, 2023; Horton, 2023) which were subsequently expanded to welcome a wide array of non-coronaviral respiratory conditions such as COPD, asthma and, increasingly, other conditions such as urinary tract infections (Nuffield Trust, 2022). Since 2021, the NHS app has also improved dramatically, centralising patient records (including vaccine passports, GP appointments and referrals) and offering an easily accessible platform to book repeat prescriptions (NHS Digital, 2019; Kc et al, 2023). However, not all of the technology-related innovations were a success. The NHS Test and Trace scheme, which was contracted to Serco and cost an estimated £37 billion to the taxpayer (almost half of the annual NHS budget), failed due to incompatibility between the app and different operating systems (Czauderna et al, 2021).

Opportunities Associated with AI in Social Care

Digitisation and implementation of technology within social care is at a relatively early stage compared with health care. Even so, it has galvanised considerable interest on the part of both government and providers (DHSC 2021; Whitfield and Hamblin, 2022). Hamblin (2020) suggests that care providers are moving towards technology integration for several reasons:

- Technology can boost capacity of care providers by reducing time spent on tasks that could be moved onto technology platforms, and by reducing human error;
- Technology can streamline processes to improve efficiency and make economic savings in the workforce;

- Technology can improve patient autonomy and patients' direct engagement with their care through wearable technology and personal devices (particularly in early stages of receipt of care);
- Technology can improve care through (for example) centralising data on people's needs, disease monitoring, and patient and family preference satisfaction.

To implement technology within social care effectively, it has been suggested that institutions such as the Department of Health and Social Care (DHSC) and providers need to identify at what stage of the 'care journey' technological interventions are most optimal and impactful (Hamblin, 2020). Given the unprecedented pressure on the social care system and persistent calls from the sector for preventative rather than reactive measures (SCIE, 2023), a technology-supported, prevention-focused approach could be highly beneficial to the social care sector if planned and carried out well. Examples of potential practical applications and benefits of technology include:

- Using predictive modelling tools may allow providers to anticipate future demand (e.g., seasonal fluctuations) and thereby prepare accordingly;
- Risk assessment tools implemented at home or in residential care settings – in the latter, tools such as The Safe Steps app, a multifactorial frailty risk assessment tool for care homes (Neiva Ganga et al, 2023) – may allow carers to regularly and accurately assess and monitor degree of need;
- Personal devices and apps may support carers and care receivers to access and develop care plans, manage medication, and access advice and recommendations on preventative lifestyle changes (e.g., weight bearing exercise and healthy eating);
- Wearable technology, smart mobility aids and risk-reduction equipment at home may empower care recipients to live independently for as long as possible.

Deciding at what stage technology can be most useful and which interventions are optimal for different settings requires timely, comprehensive, and unbiased auditing of care outcomes for ongoing trials and pilots (Glasby et al, 2023a).

Between 2016 and 2021, the NHS ran a Digital Social Care Programme where local authorities competed for small grants for a limited number of pilot studies to integrate technology into social care provision. Over 100 projects were funded at a total cost of £22.8 million. Retrospective analyses by the Institute of Public Care highlighted large discrepancies in technological literacy and degree of staff comfort in adjusting to new technologies, with a broad spectrum of attitudes recorded (NHS Digital, 2021). Overall, however, the programme was considered a success with an estimated lifetime benefit return of £103 million, and has been said to set a precedent for technological investment for exclusively social care projects (as against joint health and social care projects as was historically the norm) (NHS Digital, 2021).

Implementing technology in social care has been thought to offer greater opportunities for personalised and self-directed care, giving care recipients more control and autonomy. Leading examples of this include telehealth services or portals which allow recipients to connect with carers virtually to coordinate support and be involved in their care plan. In 2021 the DHSC estimated that 1.7 million people in England were using assistive technologies, including smart mobility aids and sensor systems, to allow them to move around their homes independently and access help in an emergency fall incident (DHSC, 2021). Smart devices, often connected to mobile phones, help individuals to adhere to their medication regimen and monitor health parameters such as their energy levels, sleep habits, mood and nutrient intake (DHSC, 2021). All of these potentially increase the independence and quality of life of those receiving care. Other research also suggests that those receiving long-term care for chronic health needs appreciate virtual and online charity support groups which allow them to connect with others with similar experiences through online fora (Fayn et al, 2021; Boyce et al, 2024). Informal care providers may also be helped by technology. Examples of virtual

support for carers in the UK include the Carers Connect community run by Carers UK, various groups run by the Carers Trust, and Mobilise, an online information repository for carers with resources ranging from tools for financial management to those for accessing mental health support. Recent systematic analyses of 14 randomised control trials of technology-based interventions (TBI) among 1,010 informal caregivers consistently indicated that, across all individual studies, TBI effectively reduced caregiving workload amongst informal carers and had a positive impact (Zhou et al, 2024).

Technology can also play an important role in helping systems to deliver services more efficiently and appropriately, to reduce unnecessary waiting times, and to direct users to the correct service (Hamblin, 2020; Afrouz and Lucas, 2023). Examples include the Help to Care app, a mobile phone app launched in 2020 to assist people in Kent and Medway who care for others (NHS, 2020; NICE, 2020). The app enables carers to log concerns and find specialised services and resources to help those they care for cope with a range of commonly-encountered, age-related issues, including falls, memory decline, and delirium. The goal of the app is to educate carers on how to support those they care for, offering opportunities to reduce the number of unnecessary admissions to A&E, whilst ensuring that individuals who do need medical assistance are seen in a timely manner. The app achieves this by offering training videos for care needs that can be managed in the community by informal or paid carers, but also alerts carers if risks have been identified that must be handled in an inpatient hospital setting (NHS, 2020; NICE, 2020).

Challenges Associated with AI in Social Care

While many technological developments appear to be very promising for the social care sector, they are not without risk or downside. Concerns raised in the literature include digital exclusion of the ageing population (the primary demographic services target group), inequalities regarding digital capacity, and questions about whether care can remain individualised, personalised and human amidst a move toward technology and big data (Afrouz and Lucas, 2023; Horton, 2023). Providers and recipients who are skeptical of technology often cite a slippery slope argument when it comes to trends (such as AI) which trigger fears of the over-digitalisation of care (Nuffield Council on Bioethics, 2018). The WHO recently advocated caution and ethical reasoning when it comes to using AI in the delivery of care (WHO, 2023), due to concerns over data security and privacy, potential dehumanisation of patients, and the need to ensure the maintenance of high care standards. Similar concerns about keeping care human and person-centered by not relying too heavily on assistive technologies have also been reported by informal carers (Egan et al, 2022), highlighting the need for thoughtful and considered implementation. Attitudes toward AI integration amongst front-line staff are reported to be mixed, not least because of a fear that staff might be made redundant and replaced by technological systems but also due to concerns regarding the perceived value of care workers (Hamblin, 2020; Horton, 2023). Human oversight clearly remains vital in care decision-making, given the need for empathy and contextual understanding when it comes to supporting individuals with complex care needs (Egan et al, 2022).

Technology implementation has generated other concerns as well. Recent literature has questioned the readiness of the sector for meaningful and widespread technology implementation (Markel, 2022). A recent roundtable of carers and technology stakeholders hosted by the King's Fund highlighted several issues which prevent providers taking advantage of new innovations (Bottery and Mistry, 2023). Recurring issues include resistance amongst staff who feel under-supported whilst being asked to adopt new skills and modes of working, a lack of funding to drive the transition from pilot studies to real implementation in day-to-day practice, and inconsistent basic infrastructure across the UK (Bottery and Mistry, 2023).

Poor engagement with front-line providers and ambiguity over the purpose for given technology-related campaigns and their translatability into practice (Glasby et al, 2023b) are also troubling. Cases have been reported of providers or trusts identifying a technology they want to utilise without first being clear about the problem or process they would like to use it to solve or optimise (Glasby et al, 2023b). In April 2024, Claire Smout (head of digital skills at Skills for Care) highlighted the barriers that smaller providers face as they cannot raise the upfront capital necessary to afford the technological infrastructure they need, even for 'basics' such as Wi-Fi (Health Tech World, 2024). In practice, this means that there is considerable heterogeneity in the degree of tech-supported and tech-led care across different providers, which also drives inequality in care standards (Health Tech World, 2024).

Research on technology uptake among informal care workers also reveals challenges. A recent study of the attitudes of informal carers supporting individuals with mild cognitive impairment with the help of Digital Assistive Technology (DAT) found that, even if some aspects of caregiving (such as communication) are improved using DAT, many of these tools do not ultimately reduce the time an informal carer spends providing care (Baudin et al, 2024). This suggests that there is a difference between reducing the total care load and making aspects of caregiving easier. Research has also indicated trepidation amongst informal carers to rely too heavily on technology at the risk of care becoming less human (Egan et al, 2022).

Looking at the field as a whole, a number of overarching conclusions can be drawn. First, the application of technology to the social care field is at a very early stage, especially in comparison to healthcare. Second, the results of some of the interventions that have been applied are promising, especially in terms of easing the workload and the routine tasks involved in care. Third, questions have been raised around ethical considerations regarding what care tasks and responsibilities should and should not be automated to keep care person-centred and recognise its relational and ethical nature. Finally, unequal access to the technology and to the skills and knowledge required to use it may limit meaningful and egalitarian uptake of technology in both informal and formal settings.

2. Workforce Issues in Social Care

The UK social care workforce is widely depicted as being in crisis (Morris et al, 2023; O'Dowd, 2023; Sutton et al, 2023). According to estimates, approximately 2 million people in England are employed to deliver care services (Skills for Care, 2023; Foster, 2024), but, with an ageing and increasingly multimorbid population, demand for care is outstripping supply (Anderson et al, 2021; Sutton et al, 2023). The vacancy rate for adult social care positions in England doubled between 2013 and 2020 from 4% to 8% (Anderson et al, 2021), and subsequent analysis suggests this shortfall has only increased (Skills for Care, 2023). The UK government admits that one of the major challenges facing care providers is the high turnover of adult social care workers (Foster, 2024). Around one-third of adult social care workers left their jobs in the UK in 2019-2020, a drift that has continued (Skills for Care, 2023; Foster, 2024).

To meet the current social care demand in England, approximately 150,000 formal care roles need to be filled, and an estimated expenditure of £1.7 billion to bring care staff up to a living wage (Anderson et al, 2021). As of July 2023, the government allocated £570 million to the Market Sustainability and Improvement Fund – Workforce Fund, which is accessible to local authorities for retention and capacity building efforts (Foster, 2024). Aside from falling short of the investment needed to offer all paid carers a living wage, there is concern that

regional disparities in vacancy levels and carer supply mean that, without proper guidance and supervision, local authorities in low-density carer areas may struggle to achieve the necessary recruitment levels (Anderson et al, 2021).

Poor integration between health and social care means that delays in securing packages of care in the community have a domino effect, causing a backlog in the medical system which impedes the discharge of patients from hospitals, leading to fewer available beds for patients who need them. Workforce surveys also indicate that many carers feel that those investments in social care that have been made have been implemented primarily to bolster or alleviate the burden on the NHS, rather than to improve the care sector itself (Markel, 2022). Whilst it is important to acknowledge the interplay between both systems, improvements are needed in social care in and of itself, rather than as an indirect means to improve the healthcare service.

Intersectional Challenges and Workforce Shortages

Workforce shortages have been accelerated by immigration challenges following Brexit. Such challenges are projected to reduce the number of social care workers by 115,000 by 2026 (Bains et al, 2018; Hemmings, 2020, Migration Advisory Committee, 2022). There has also been considerable burnout and low morale following the COVID-19 pandemic, which saw social care staff working under extreme pressure in often traumatic and dangerous working conditions (House of Commons HSCC, 2021; Morris et al, 2023; Skills for Care, 2023). Evidence suggests that the impact of both Brexit and post-Covid fatigue has been further exacerbated by unfavourable perceptions of social care work as being thankless and involving hard labour for low wages and poor working conditions (Hayes, 2017; Purvis, 2017; Oung, 2020; Bottery, 2023; Morris et al, 2023; O'Dowd, 2023).

A problematic combination of low wages and feeling undervalued is a considerable factor in many social care workers' decisions to leave the sector and pursue service roles in other sectors (Hayes, 2017; Purvis, 2017; Anderson et al, 2021; Markel, 2022). Compared with other service sectors such as hospitality or retail, social care wages are some of the lowest paid in the UK (Anderson et al, 2021), with 54% of social carers on unpredictable zero hours contracts (House of Commons Library, 2024). A recent interview with a UK social care worker highlights the problem: "You can make more money working in a supermarket than you could by looking after someone on their last days with dementia" (Markel, 2022, pg.10). Many carers are placed on zero hours contracts, giving them little job security. Moreover, with the UK currently experiencing a cost-of-living crisis in which wages are struggling to keep up with inflation and basic living costs, many front-line staff have been forced to reconsider their career in care (Care Management Matters, 2022; Markel, 2022). A 2022 survey of formal domestic care workers points to rising costs of living and low wages as the top causes of resignations in the formal care workforce, with many seeking better paid jobs in other sectors (Homecare Association, 2022). The situation was especially bad during the COVID-19 pandemic (Hu et al, 2023). In one study, nearly 60% of carers reported feeling unsafe at work due to concerns that co-workers would come into work with symptoms; the root concerns were financial concerns around lost hours (Homecare Association, 2022). Close to half (48%) said they were seeking alternative employment due to issues regarding loss of pay while isolating (Homecare Association, 2022). Surveys by both the Carers Trust and Carers UK indicate these financial challenges hit both informal and formal carers but disproportionately impacted unpaid and informal carers, with 45% of these carers unable to manage monthly expenses and over 46% reporting that rising living costs were directly compromising the health of their care recipient(s) (Carers UK, 2022; Carers Trust, 2023).

Many care workers highlight the lack of progression and poor financial recognition of experience and training as barriers to longer term staff retention (Oung, 2020; Markel, 2022;

Morris et al, 2023; Sutton et al, 2023). Recent analyses indicated that on average the pay differential between carers at the beginning of their career (with under a year's experience), compared with experienced care workers with at least 5 years hands-on experience, was only £0·12 per hour (Anderson et al, 2021; Skills for Care, 2023). Lacking financial and promotional incentives to upskill or diversify skillsets, many workers leave to pursue alternative careers they perceive to have greater development potential. Recent estimates highlight that the sector particularly struggles to retain young people, with turnover rates of 53.7% in individuals aged 18-20, indicating that care work is seen as a stop-gap before young workers pursue other avenues (Markel, 2022; Skills for Care, 2023).

The lack of clear pathways to greater seniority and higher pay makes progressing along a social care career unattractive and prevents workers from seeing how their work today might pay off tomorrow. The corresponding lack of meaningful recognition of length in post or contribution to the sector likewise detracts from the otherwise rewarding aspects of social care work. In response to such issues, the UK government recently launched its Care Workforce Pathway, in collaboration with Skills for Care (DHSC, 2024a). The purpose of the pathway is to offer clear, standardised guidance on the roles and responsibilities of different social care roles from A to D (newest to the sector and most senior, respectively). The hope is expressed that the pathway will act as an actionable framework for progression, with accessible examples of learning and development opportunities at each stage as a carer progresses through the roles (DHSC, 2024a). Without appropriate financial renumeration and improved working standards, however, the pathway is unlikely to have a significant impact on retention.

Co-production audits of the social care workforce have highlighted that carers believe retention would improve if there were more accessible formal qualifications and development opportunities which facilitate recognition of experience and advanced training (Markel, 2022; Skills for Care, 2023). One such example at the sector-entry level is the Care Certificate, a Level 2 certificate comprising 15 minimum workplace standards that should be met during an induction to care work for all new social carers. Upon achieving the certificate, participants should understand the 'knowledge, skills and behaviours expected of specific job roles in the health and social care sectors' (Skills for Care, 2023). Recently, Skills for Care announced the launch of a new formally accredited Level 2 Adult Social Care Certificate qualification (Skills for Care, 2024) which is an evolution of the general Care Certificate, dedicated specifically to adult social care. The scheme, run in partnership with the DHSC, aims to accredit 37,000 individuals between June 2024 and March 2025 and is the first of its kind in the UK (DHSC, 2024b).

Technology and Workforce Issues in Social Care

A review commissioned by NHS England points out that many of the health and social care workforce lack sufficient technological literacy and training to adequately engage with new tools in their work (Topol, 2019). Apart from scarce opportunities for training in technology in the social care sector (Markel, 2022), the situation also reflects a general lack of standardised training for social care providers and variable levels of background educational attainment and formal care qualifications (Skills for Care, 2023). It is highly likely that most front-line providers, especially those of older generations, have limited technological literacy (Maguire et al, 2021; Markel, 2022; Glasby et al, 2023b).

Since the 2019 Topol review, the NHS has put considerable resources into improving technology-related literacy amongst its healthcare workforce (Topol, 2023). It now sponsors opportunities such as the Digital, Artificial Intelligence and Robotics Technologies in Education (DART-Ed) programme for clinical and allied health professional staff (NHS England, 2023) as part of the Building a Digital Workforce campaign. Again, however, health

sector workers are prioritised, with comparatively fewer training and development opportunities for social care workers. An introduction to digital and technology learning is included in the new Level 2 Adult Social Care Certificate qualification, reflecting a desire to upskill the future workforce in this area (DHSC, 2024b). However, a recent survey by Markel highlighted how many social care staff feel overlooked compared with NHS and healthcare workers, the latter being empowered through funded programmes to take up training opportunities not offered to carers working in the home or private sector (Markel, 2022).

By way of overview, we may note, first, the numerous challenges facing the social care workforce. These have been exacerbated by a cost-of-living crisis and recent immigration changes which have reduced the supply of international workers. Pathways to long-term careers in social care are lacking and there is limited formal guidance and career development frameworks. While some initiatives for upskilling and boosting workforce prospects and morale are underway, without significant reform of the public image of social care work supported by meaningful pay increases and other improvements, the sector is unlikely to be able to keep up with exponentially rising demand.

3. Informal Care

Informal care is offered outside a formal setting (such as a nursing home). Informal carers are most often relatives and family members, friends, or members of the community surrounding a person receiving care (Cruz et al, 2023). In recent years there has been an active effort amongst advocacy groups, researchers and policymakers to attract greater attention to informal carers and the situations they experience. Despite those efforts, informal care remains largely under the radar. Estimates of the number of informal carers in the UK vary widely – between 4 and 10 million (Nuffield Trust, 2022; House of Commons Library, 2023) – due to a lack of trustworthy evidence. Understanding of the contribution of marginalised or minitorised groups is particularly poor, hindering meaningful engagement with these communities and limiting decision makers' understanding of the overall informal care load (Urwin et al, 2021). For many years, informal and unpaid carers have helped hold up a struggling formal social care system by alleviating a considerable portion of the care load. According to recent projection analyses undertaken by the London School of Economics, the cost of informal care in 2019 was £54.2 billion, which is three times the expenditure on formal long-term care (Hu et al, 2023). As Hu and colleagues explain, 'costs' here refer not to governmental expenditure, but rather to a combination of informal carers' time, lost earning potential spent caring, and resources required to deliver this care (Hu et al, 2023). These costs are projected to rise by 87% by 2039 (Hu et al, 2023).

The reasons why informal carers take on responsibilities for caring for others are complex and varied (Peterie and Broom, 2023). The most common is a sense of devotion or commitment to a loved one (Bei et al, 2021). Other common motivations include those in need of care having insufficient funds to pay for formal provision (Aldridge and Hughes, 2016), cultural norms which create a sense of responsibility (Zarzycki et al, 2023), and concerns over the quality of care available in formal care environments (House of Commons Library, 2023). In many cases, offering informal care is not a choice but a way of life for those who wish to or who feel obligated to be a primary caregiver.

Demographically, the informal care community is disproportionately composed of women, especially those from ethnic minority backgrounds or those living in areas of high deprivation (Hayes, 2017; Penfold and Magee, 2020). Inequalities in this regard may be attributable to traditional gender roles (Penfold and Magee, 2020), which see fewer men taking on informal

care responsibilities, particularly in the older generation (Hayes, 2017). As a result, care responsibilities often fall on daughters or younger women in families (Hayes, 2017; Penfold and Magee, 2020). The provision of care around the globe is also disproportionately shouldered by women in unpaid caregiving roles, as highlighted by the United Nations (UN) (UN, 2015), World Health Organization (WHO) (WHO, 2024a) and International Labour Organization (ILO) (ILO, 2018). The UN views this in relation to the much larger issue of undervaluing of care and women's work in general. To ameliorate the situation, the fifth UN Sustainable Development Goal (SDGs) aims to achieve gender equality by empowering women and girls. Appendix 5.4 in particular states that member states must 'recognize and value unpaid care and domestic work through the provision of public services, infrastructure and social protection policies and the promotion of shared responsibility within the household and the family as nationally appropriate' (UN, 2015).

Impact of Caregiving on Informal Carers

Research makes clear that informal care has emotional, mental, physical and economic implications (Nuffield Trust, 2022). A recent systematic analysis (Lindeza et al, 2020, pg. e40) of 81 international studies spanning 1998 and 2020 with a total of 3,347 participants highlighted the lifechanging impact of caregiving: "It effectively changes your life. Your priorities change. Your lifestyle changes. Your attitude to the person you are giving care to changes. Your role changes." While analysis of the included studies revealed positive remarks about the caregiving role in 18 of the included studies, negative remarks were present in 76 of the included studies, with some featuring both aspects. According to the Carers Trust, young care providers are less likely to achieve the same educational attainment as their peers who are not acting as carers (Carers Trust, 2023). Caregiving has also been found to impose restrictions on the ability of carers to undertake other work, which can limit their own financial stability and career security (Aldridge and Hughes, 2016; DWP, 2019; Carers UK, 2022).

The government offers some financial support for informal carers (in the form of a Carer's Allowance) should they qualify for it. Amidst the recent cost-of-living crisis, a high proportion of informal carers reported being unable to reliably meet their basic needs such as food or utility costs (Carers UK, 2022). This financial strain also leaves informal carers concerned for the health and wellbeing of the person they are caring for (Carers UK, 2022). If informal care is being offered in a context of familial poverty or financial instability, caregiving can perpetuate negative cycles of intergenerational deprivation by compromising the economic potential of the caregiving generation.

Incorporating Informal Care into Future Care Models

One of the advantages of informal care is that it is usually offered in familiar settings (typically the home of the care recipient or care receiver) and can be more personalised due to the personal relationships between both parties. However, informal care is unregulated and unsupervised. Whilst many informal carers give excellent care that would not be reproducible in the formalised system, in cases where a care recipient has extensive or considerable levels of need, informal caregivers can easily become overwhelmed, compromising the quality of care provided and the wellbeing of both carer and care recipient. Informal carers, especially those closely related to a care recipient, might feel shame or guilt at voicing concerns over their ability to provide care, especially if there is a cultural expectation of such care being forthcoming.

A more realistic long-term model for caregiving may involve better integration between informal and formal modalities, rather than substitution of one for the other (Lyu et al, 2023).

This would preserve the familiarity and comfort of informal settings, with necessary support for meeting advancing needs. Maintaining this balance might be more sustainable than placing the responsibility entirely on unpaid carers' shoulders and may also limit over-stretching of formal services if a recipient's needs are judged to be manageable from a non-formal environment. Such arrangements do, however, raise questions about who should be practically and financially responsible for care provision. Some support services and policies are in place to recognise and support informal caregivers such as respite care services (NHS, 2023). However, state-provided respite services require a care needs assessment of the care receiver, by the local authority, and a carer's assessment (NHS, 2023). These formalities can deter some informal carers from pursuing council-funded support due to concerns surrounding family members or loved ones being taken away, judgement of the quality of care they are currently providing, or shame and guilt surrounding asking for help. Beyond the help available through local authorities, specialised charities such as AgeUK or MindForYou may be able to offer respite packages for unpaid carers (NHS, 2023).

By way of overview, informal carers provide a great deal of the care work that is undertaken today. This heavy reliance on informal carers is not unique to the UK but is especially notable in this country. Furthermore, informal care is highly gendered, as well as being disproportionally undertaken by people from some ethnic groups more than others. Current challenges facing informal carers (and those they care for) include the cost-of-living crisis and financial strain, limited access to formal support without using private resources, and potential deleterious impact of care on caregivers' well-being and socioeconomic status. Policy efforts and support services aim to recognise and assist informal caregivers but major gaps exist. Better integrating informal and formal care models might offer sustainable solutions, but various considerations must be addressed for this to be meaningful.

4. Social Care Infrastructure in the Global South

The term Global South refers not just to the hemispheric south, but to decolonised nations located roughly south of the old colonial centres of power (Haug, 2021). These countries, which are perhaps more frequently categorised as Low or Middle Income (LMIC), face a myriad of challenges in developing sustainable social care infrastructures. Such challenges include issues that are unique to a given national and regional context (as highlighted by Lutz and colleagues (2021)), and those resulting from larger-scale global divisions. These latter divisions may be economic, geo-political, socio-cultural, or infrastructure-based.

Economically, countries of the Global South tend to have less national income or GDP to spend on social care infrastructure relative to nations like the UK (Jakovljevic et al, 2021; OECD, 2020). As recent data from the London School of Economics highlight (Papanicolas et al, 2019), OECD countries that spend more of their total GDP on healthcare typically spend more on social care, while the converse is also true (OECD, 2020).

Countries in all regions of the world have historically prioritised spending on healthcare over social care (Papanicolas et al, 2019; OECD, 2020). LMICs often face drastic or acute health challenges due to a range of factors – resource constraints, infrastructural issues, geopolitical instability, and geographical proclivity to certain diseases and conditions (GBD 2016 DALYs and HALE Collaborators, 2017; Aluisio et al, 2019; Nakahara et al, 2019; Lewis et al, 2023), among others – which make them even less likely to invest in social care. For example, countries in climates disproportionately affected by tropical or endemic diseases are more likely to invest in pandemic preparedness, medicines, and vaccines than social care infrastructure for an ageing population, as the latter seems less urgent (Jakovljevic et al, 2021). Much of the outreach work of NGOs and charitable initiatives continues to focus

on explicit health support, education, and poverty alleviation. Global South nations might also decide to increase spending on sectors such as defence and military due to living within or proximal to active conflict zones. That decision makes establishing social care infrastructure (such as assisted-living facilities or support centres) less of a priority compared to the high-income nations (Lutz et al, 2021).

Informal Care in LMIC Settings

The research indicates that in LMIC settings, social care is primarily (if inconsistently) provided in the community and at home, and less so through social protection initiatives and formal care settings (Noble et al, 2014; Hujo, 2021; Niño-Zarazúa et al, 2023). Social care in LMICs is more likely to be informal due to several factors:

- Limited access to formal care infrastructure, particularly that of social care, particularly in rural areas;
- Reduced national spending on social care resulting in limited state-funded care facilities;
- Limited personal disposable income to pay for care in formal settings;
- Under-diagnosis and poor recognition of age-related decline e.g., mild cognitive impairment, dementia, reduced mobility, incontinence, etc.;
- Socio-cultural attitudes toward age-related conditions requiring social care;
- Socio-cultural attitudes toward formal care such as ascribing family the role of care provider (especially women);
- Stigmatisation around cognitive impairment, of direct sufferers and their carers.

One of the key issues related to the creation of social care infrastructure in the Global South and the reality of working in formal social care in these regions centres on accessibility and connectivity (Ravalier et al, 2022). It is especially difficult to integrate health and social care within rural communities. Rural areas are more likely to suffer also from digital exclusion, which can make virtual communication and integration efforts challenging (Ravalier et al, 2022). Technology-related literacy amongst communities remains variable and limitations surrounding electricity provision, broadband and internet connectivity can create logistical challenges when setting up infrastructure (Stein and Lazar, 2021).

Perception of Age-related Conditions and Associated Care Needs in LMICs

Research indicates there is a different perception of ageing and age-associated diseases in LMICs which is reflected in (lower) governmental spending and service provision (Ferri and Jacob, 2017). Dementia is a good case study for understanding this. In many LMICs, dementia is perceived less as a disease or condition and more as an aspect of normal ageing (Ferri and Jacob, 2017). As a result, many families provide care for loved ones suffering with severe dementia, care that would typically be managed in nursing homes in a better-resourced country such as the UK (World Dementia Council, 2022). Whilst there is a general lack of understanding and awareness of dementia as a real disease in most LMICs (likely due to underdiagnosing), region-specific cultural perceptions also play a role in care being largely informal

A recent retrospective analysis by Mattap et al (2022) evaluated the indirect and direct spending on dementia across different LMICs and High-Income-Countries (HIC) and found lower total costs of dementia in LMICs (as a proportion of total GDP). This supports existing data on the lower spend of LMICs on age-related conditions such as dementia, compared with other non-communicable diseases including cancer, diabetes, respiratory and cardiovascular diseases (Bloom et al, 2011). The study by Mattap and colleagues also

reported higher relative indirect costs of dementia in LMICs, calculated according to the informal caregiving burden compared with direct costs which were determined by formal healthcare spending. However, the authors point out that incomplete data makes it very difficult to calculate indirect costs, increasing the likelihood that these have been underestimated due to poor reporting on informal care burdens, particularly in LMICs. Nevertheless, these data indicate that, in combination with reduced access to formal infrastructure, increased informal care provision in the home and culturally influenced perceptions of dementia as normal ageing could explain the reduced associated direct costs expended by LMICs (Mattap et al, 2022).

Socio-cultural Attitudes to Formalised Care

In the absence of widely available formal services, much of the social care provision in the Global South is informal and family based (Noble et al, 2014), which links to the socio-cultural forces at play in these countries. In many such countries, traditional norms surrounding care responsibilities persist and often intersect with identity, religion and gender (Bedford et al, 2022). A good example of this is the Confucian principle of Filial Piety, which requires that "adult children care for their aging parents' physical, emotional, and social needs as well as their happiness throughout their lives … The concept embodies three bonding relationships within a family unit: son to father with reverent obedience, wife to husband with mutual obligations, and younger to elder with authoritarianism" (Xiao et al, 2024, pg. 2). Whilst families in China and South Korea are increasingly moving away from the concept of Filial Piety, there remains considerable stigma associated with not upholding social care responsibilities to elders, especially in more rural areas. Similar virtues of familial duty are seen across the world (Bedford et al, 2022).

Whilst international agencies such as the UN (through its SDGs) and the WHO have drawn attention to global gender inequality and the unrecognised role of women as informal carers in the Global South (UN, 2015; ILO, 2018; WHO, 2024a,b), a nuanced and delicate balance must be struck when proposing initiatives to improve social care infrastructure. Paternalistic white saviour orientations have, historically, perpetuated harmful narratives of Western superiority when it comes to governance in the Global South, which has often led to interventions that undermine local practices and values (however well-intentioned) (Haug, 2005; Lutz et al, 2021). Similar to the situation in Europe, as of 2018, 80% of the informal care burden in Asia and the Pacific was shouldered by women, and globally 606 million working-age women were unable to take on paid work because of unpaid care commitments (ILO, 2018). This mirrors a 2024 editorial by the WHO on the invisible informal contribution of women in Thailand (WHO, 2024b).

Limited LMIC-focused Social Care Research in the Region

An often-cited issue in the literature is the paucity of research exploring health and social infrastructure within LMICs themselves (Aluisio et al, 2020; Fanelli et al, 2020; Olufadewa et al, 2021). This reflects limited efforts to meaningfully engage communities in the region to understand the social care challenges they face. Recent work by Olufadewa et al (2021) highlights three key barriers to primary research generation in LMICs: i) discrepancies in research capacity and training between LMICs and HICs which often prevent LMIC-based researchers leading studies, ii) historically limited collaboration between LMIC researchers in common fields, iii) funding limitations in terms of the proportion of GDP spent on research in these regions. While research on the social care challenges facing LMICs can be done remotely from HICs, there is a growing move toward co-production but research output directly from these areas is needed to build local expertise, capacity and education about these challenges (Aluisio et al, 2020).

Dementia is one of the few funded areas of research, (albeit underfunded), for degenerative conditions of older aged people in LMICs. As Prince et al (2009) discuss, only a handful of intervention trials seeking to educate formal carers on dementia care have been conducted in LMICs. And yet retrospective analysis indicates that the positive impact of training carers in these areas is far more significant than similar interventions replicated in HICs where baseline care infrastructure and dementia awareness is usually higher (Prince et al, 2009). In line with this, recent commentary from the Alzheimer's Association highlighted the importance of improving coverage of dementia in LMICs and the presence of LMIC-based dementia research on the global stage (Sexton et al, 2021). Multi-national projects such as STRiDE, which seeks to build dementia research capacity to generate the evidence-base for dementia long-term care in the Global South, are examples of effective co-production research in LMICs, and offer frameworks for future efforts. Among the offshoots of the project (other than reducing the burden on informal carers in the Caribbean) are DEM-SKY – a Kenyan community dementia screening programme which has supported with early dementia diagnoses and facilitated more timely access to dementia-specialised care services (Kalaria et al, 2024). It is hoped projects like these bolster future funding bids to sustain this research as dementia cases and care demand continues to rise in LMICs (Breuer et al, 2022).

Taken as a whole, the following are some of the points to be emphasised on developing a social care infrastructure in the Global South. Data on social care provision in the Global South and LMICs is very limited and incomplete, leading to challenges when trying to accurately analyse social care burden, resources, infrastructure and the workforce in these areas. The literature suggests that social care takes a back seat compared to healthcare on national agendas in these regions, and there are clear indications that social care is largely offered informally and within the community. Research areas such as dementia, which sit at the interface between health/medicine and social care, have been gaining more attention from researchers and policy makers in the region. But research and knowledge sharing efforts centred on social care are scant.

5. Considerations for the Care Initiative

As the discussion has indicated, there is much research on but also many outstanding questions regarding each of the four topics considered for this report. There are therefore some strategic decisions to be made regarding which topic the Care Initiative might focus on. Among the strategic issues here are whether the Initiative should limit its activities to the UK. There are also questions about whether the relevant issues should be treated singly or as conjoined issues under a broader heading around the organisation and modernisation of the adult social care system in the UK. Part of the problem with the social care system in the UK is that it is very fragmented. Bringing together different topics would mean that the social care system is regarded as a whole and especially that formal and informal care and carers are placed side by side, rather than treated separated as at present. Proceeding in this way and considering especially what a functioning and adequate social care infrastructure would look like in the UK would also enable lessons to be learnt for other countries and parts of the world.

The following are some key outstanding questions that emerge from the review undertaken. They set out a range of issues that merit close examination.

How can the human and relational elements of care be preserved in an increasingly technological social care?

Sub questions of this discussion might include:

- How can technology-related developments empower and support, rather than replace, the existing care workforce?
- What is the optimal balance between technology and human-provided care?
- Should certain tasks/conversations be reserved for human-provided care, and what are the ethical implications underpinning this?
- How can technological interfaces be sufficiently personalised?

In light of an historic reliance on international workers, how can providers overcome the loss of the foreign worker workforce contribution post visa changes?

Sub questions of this discussion might include:

- Can workers from outside the European Economic Area (EEA) substitute for the lost EU workforce?
- How can providers and institutions appeal to prospective domestic UK care workers?
- What are the implications for recent immigration policies (NHS Employers, 2024) on retention and attractiveness of UK social care institutions as prospective employers?

Is the care workforce pathway working and under what conditions could it work better?

Sub-questions of this discussion might include:

- How is the pathway being implemented nationally, regionally and locally?
- Are social care workers aware of the pathway and is it having a tangible impact on their day-to-day practice and longer term intentions?
- Has the pathway had an impact on retention and workforce satisfaction?
- Does the pathway make carers feel their progress is being recognised?
- Are all roles being supported equally?

Is there sufficient technology-related literacy in the workforce for tools to be widely and effectively implemented?

Sub questions of this discussion might include:

- What is the receptivity of paid care workers, unpaid carers and care receivers to increased use of technology in social care?
- Who is driving the move toward technology? Is the technology being rolled out in response to workers' and carers' needs or is this a priority for management and product development?
- How does the increasing introduction of technological change the current and future content, structure and responsibilities regarding social care provision?
- Does technology implementation offer an opportunity for upskilling the workforce and the opportunity to gain transferable skills?
- How does the implementation of technology and innovation in social care impact job security and progression to senior roles?

What is the nature and distribution of informal care giving for women in the UK and its impact?

Sub-questions of this discussion might include:

- What are the short- and long-term impacts of providing informal care for UK women, especially women of minority ethnic groups and low socioeconomic status?
- What are the unique challenges faced by women living in poverty who provide informal care compared to men in similar circumstances?
- Do men feel empowered to offer informal care? If not, what are the barriers to facilitating this?

- To what extent do cultural norms and societal expectations influence the distribution of informal care responsibilities among women and men in areas with high deprivation?
- What are current policies/strategies designed to alleviate responsibilities and inequalities associated with informal care, and are they reaching the target group?

How can informal care be better integrated with formal care services to provide more holistic and coordinated support to care recipients and their families?

Sub-questions of this discussion might include:

- What are the attitudes of care receivers and informal carers towards better integrating with formal services?
- How does the quality of informal care compare to formal care services in terms of effectiveness, satisfaction, and outcomes for care recipients and care givers?
- How does the availability of informal care within a given community or demographic group impact the utilisation and demand for formal care services, and what are the implications for resource allocation and policy development?
- How can technological advances assist with integration of informal care modalities?
- What are the barriers facing informal carers of different demographic backgrounds (e.g. socioeconomic status, ethnicity, cultural or religious group) in getting access to formal support services and resources and how can these barriers be addressed to better support caregivers in their roles?

What is an appropriate and effective infrastructure for care provision in the Global South?

Sub-questions of this discussion might include:

- What are the attitudes toward informal and formal social care work in different areas of the Global South and how is this work described (whether it be properly defined or not)?
- What is the optimal balance of formal and informal care provision in different areas of the Global South and across different age-related conditions?
- How can families and informal carers be supported but not exploited in a way that simultaneously also provides opportunities to grow formal provision?
- How can the work of informal carers coming from marginalised groups (such as women of colour) be better recognised and supported?

What forms should co-production and social care research partnerships with LMICs take?

Sub-questions of this discussion might include:

- What are the key impact issues in adult social care that merit co-production research in LMICs? How broader social care research efforts, not focused on a specific disease or condition, be conducted in LMICs?
- How can social care initiatives involving Western partners or those from the Global North ensure that their actions and approaches actively challenge and dismantle colonial structures, rather than inadvertently perpetuating racial oppression and disadvantage in nations with colonial histories?
- How can target regions and communities for partnership be identified?
- What can be learnt from existing co-production partnerships working in the Global South?
- What form of support would be most valued by researchers in LMICs to meaningfully support evidence generation and knowledge dissemination.

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