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Research ethics in social care

METHODS REVIEW

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Keywords

research ethics; research governance; research ethics committees

Disclaimer

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ABSTRACT

This review clarifies the requirements for the ethical conduct of social care research that involves human participants. The review aims to provide social care researchers with information about the overarching ethical rationales for considering the ethical permissibility of their research activities, and identifies a number of specific ethical principles that social care researchers should consider in order to design their research studies in ways that stand up to detailed ethical scrutiny.

The review also considers the distinctiveness of ethical issues in social care research practice, drawing on illustrative examples to consider how these issues ought to be thought through using the ethical principles identified.

Finally, practical guidance is offered to how social care researchers ought to approach the process of obtaining ethical approval from a research ethics committee, providing them with tools to enable them to articulate, justify, and defend their research practice and the methodological decisions that they have made in designing specific social care research studies.

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1. INTRODUCTION

It is a well-established principle in universities and other research institutions around the world that all research involving human participants must be subject to ethical oversight before it is allowed to proceed. In order to put this principle into practice in the UK, Research Ethics Committees (RECs) have been established to scrutinise research studies at the university, local authority and governmental level. In contrast to the health care research context, comparatively little work has been undertaken about how to think about social care research ethics. Yet, in order to be able to carry out their research studies within the established research governance frameworks, it is important that social care researchers are familiar with research ethics.

Guidance papers within health and social care research tend to focus on providing an overview of the governance process associated with RECs of different kinds, rather than offering a broad introduction about how to think about the ethical aspects of social care research itself. As such, researchers are likely to be familiar with the procedures that need to be followed in order to gain ethics approval, but lack insight of the relevant ethical arguments, or how to apply these, when thinking through the design of their studies, or when they are called to account and justify their research protocols by members of the REC.

This Methods Review will aim to address this gap in the literature. The Review's primary aim is to go some way to demystify research ethics for social care researchers by providing a concise overview of the field of research ethics in social care in a way that is orientated towards the practical challenges that social care researchers are likely to have to address in designing their research studies. The Review will also provide guidance to these researchers on how to navigate research ethics within their work by focusing down on the ethical arguments and principles that can be used to plan and defend the design and conduct of their studies.

This Review sits alongside and complements the 2011 SSCR Methods Review, Research governance and ethics for adult social care research: procedures, practices and challenges[1], prepared by Dr John Woolham. Dr Woolham's Review provides comprehensive insight into the governance framework for research ethics within different adult social care research contexts in England. Those reading Dr Woolham's Review should also familiarise themselves with the Health Research Authority's UK Policy Framework for Health and Social Care Research, first published in 2017 which updates many of the requirements for health and social care research governance. In contrast, this Review focuses its attention on various theoretical and practical aspects of research ethics decision-making in social care.

The fundamental ethical tension at the heart of social care research

Why have ethicists devoted so much time examining the rights and wrongs of research activities? In contrast to many defences of research ethics, this is not because of a common tendency of researchers to act wrongly – as a variety of ethical scandals in the conduct of research might lead people to believe. The best answer to this question lies in recognising a basic, fundamental ethical tension that exists at the heart of all research activities. This tension can be understood as an ethical conflict between the interests of those individuals who are recruited into a research study (as a necessary part of its conduct), and the interests of the future, potential beneficiaries of the research study (as a downstream effect of its outcomes).

What is the precise form of this tension? Participation in a social care research study will involve those who agree to be recruited into the study to adopt a role of some kind. They might, for example, be required to complete a survey, to take part in an interview, to be subject to a period of observation, to have their social care record scrutinised and for data to be collected from it, or to participate in a novel social care intervention that is being trialled in order to establish its efficacy. Participants may gain some benefit from taking part in the research activity, but more often than not they will gain very little from participating. Indeed, the process of participating in these activities might be burdensome for the research participants, or it might lead to their interests or rights being compromised in other ways. Of course, the rationale offered by the researchers for conducting a particular social care research study will be commonly made in terms of the

[1] www.sscr.nihr.ac.uk/SSCR-methods-review_MR004.pdf

benefits that will accrue for those who provide or use social care services. With research evidence to hand, the quality of social care practice will be advanced, with benefits accrued for the future users and providers of social care (but not necessarily for those who participated in the research that produced this evidence).

The core ethical tension in social care research described above differs in important ways from the range of ethical tensions that commonly arise in social care practice. In social care practice, ethical difficulties can arise for a number of reasons. Commonly, it can be difficult to specify how best to advance the interests of the social care service user, or perhaps also those of the caregiver. For example, there might be recognised ethical duties to both enable the service user to make choices and pursue activities that are aligned with her own personal values and preferences, and to ensure that the service user is safeguarded from risks that can arise in the undertaking of social care activities. When the service user expresses preferences to participate in high-risk activities, an ethical judgement about how to balance the values of choice-making and risk protection needs to be made. In other situations in social care practice, the tension will be between the interests of one service user being in conflict with other service users, particularly in communal living environments, or between the interests of the service user in receiving care at home (in line with their preferences) and the interests of family members/caregivers who might be burdened by taking on the caregiving role in order to meet these preferences.

The fundamental tension in social care research will require trade-offs to be made in the research design phase between protecting the interests of research participants and ensuring that the research is undertaken in a way that maximises its potential value for those who might benefit in the future from the collection of high quality evidence. Analysis in social care research ethics seeks to explore and explain how this trade-off should be made in ways that stand up to ethical argument and justification. This will involve a number of related activities.

First, attention will need to be given to specifying the overarching moral theories that can helpfully provide a range of ethical reasons for thinking about how to prioritise the interests at stake in social care research. An overview of three dominant theoretical standpoints is provided in Section 2. Second, the ethical principles that can be agreed upon as emerging from these overarching moral theories need to be specified. These principles will function as ethical 'waypoints' for social care researchers, in the sense that they point out the ethical considerations that need to be navigated around in making research design decisions. A discussion of the commonly agreed ethical principles for social care research is provided in Section 3. Finally, the common ethical issues that arise for social care researchers in determining their sample, research procedures, and methodological approach need to be identified and reasoned through. This requires attention to be given to how the identified ethical principles should be drawn upon to make an argument for how a specific ethical issue ought to be addressed (see Section 4), and guidance to be provided to researchers on how to articulate and defend this argument as an integral part of the ethics review process (see Section 5).

2. THREE MORAL THEORETICAL PERSPECTIVES FOR NAVIGATING SOCIAL CARE RESEARCH ETHICS

In this section, three overarching ethical positions to resolving the ethical tension at the heart of social care research will be presented and discussed (Wilkinson et al. 2019). These three positions reflect overarching moral theories that emphasise a particular way of understanding which ethical values in research should be prioritised.

The libertarian (rights-based) position

This position stresses the fundamental ethical importance of safeguarding the freedoms and autonomy of both researchers and research participants, and to draw on these values in order to judge when a piece of research would be ethically defensible to proceed. As a starting point, the libertarian position defends the view

that researchers have a fundamental right to undertake research as members of society, and that this "right to research" can only be constrained when it impacts on the freedoms of other individuals.

On this account, the researcher should be free to make any offer to research participants in the pursuit of their right to research. However, the libertarian view also insists that the research participants are free to decide whether to accept or not the offer that the researcher makes to them, irrespective of any other ethical consideration or ethical objection to the research project that might be put forward. From the libertarian standpoint, it does not matter whether there is any objective, scientific rationale for the research activity, nor whether research participation would involve significant risks of harm to those individuals who take part. So long as the research participants are able to make a free and autonomous choice about their participation, the researcher should be free to pursue any research activity that they wish.

One important implication of this argument that is particularly pertinent in social care research is the possibility that the research participants will have cognitive impairments that mean that they do not have the ability to make a free choice about whether to participate in the research. Because the libertarian approach places such great ethical weight on free participation, individuals who lack the capacity to make a decision about their participation would never be permitted to be recruited into research.

The paternalistic (duty-based) position

This position recognises a fundamental ethical duty to ensure that the potential research participants are not exposed to harm in the conduct of the research. The paternalistic position is concerned with minimising the harms that might be experienced in research participation and takes the view that research that exposes participants to more than minimal harm is always ethically impermissible.

This view clearly conflicts with the values espoused by those who advance the libertarian position. On the paternalistic view, a researcher's freedoms to undertake harmful research will always be constrained, and no research participant will be permitted to participate in such research, even if they express a clear, perhaps altruistic, view that they would be happy to agree to participate, knowingly exposing themselves to high risk. Equally, however, the paternalistic view would have no ethical concern with very low-risk social care research in which the participants do not knowingly participate, or when they are not actively approached to give permission to take part of the research – perhaps, for example, where they are discretely observed in a public space by a researcher.

The utilitarian (consequences-based) position

This position advances the view that the ethical permissibility for research will depend on considering the consequences that result from the research proceeding. The utilitarian considers these consequences in terms of the overarching 'utility' that the research is expected to bring about. Here, utility is typically understood in maximising the amount of good things that relate to the research activity taking place (such as overall pleasure or happiness) and minimising the amount of bad things that accrue (such as overall pain and unhappiness).

When applied to the social care research context, the utilitarian approach requires attention being paid to the benefits and harms that are likely to accrue from the research overall. This means considering the benefits and harms that are experienced by those who participate in the research, and the benefits and harms that will result to those who will be impacted on by the production of (high-quality) research outcomes in both the short and long term. Harms and benefits experienced by the researchers themselves in conducting the research activities would also be required to be considered as part of this calculation. The research is permitted to proceed on ethical grounds only when the overall benefits outweigh the overall harms.

At least in principle, this approach justifies exposing research participants to very significant harms if the overall benefits from the research taking place outweigh these harms. The degree of harms that commonly result from participating in social care research are likely to be less significant than those that might arise in other research contexts, such as clinical trials, though it is also possible that the potential benefits from a piece of social care research are more limited in nature and scope than those that could accrue from researching a new treatment for a serious health condition.

One significant challenge in making the overall harm-benefit calculations that the utilitarian approach demands is how to reasonably foresee and quantify the short- and long-term effects of the research taking place. For example, the harms that research participants experience in any particular social care research study could be justified by the benefits that result from producing new evidence, but not if these harms become public knowledge, and have the negative effect of lowering recruitment rates in a wide range of less harmful social care research studies.

Applying the three positions to social care research practice

How these three theoretical positions would require the ethical justification for social care research to be reasoned through can be usefully clarified by attempting to apply each approach to a specific study. In Box 1, a hypothetical social care research proposal is outlined. Below, the different dimensions of this research plan will be considered from the perspective of each approach.

Box 1: Ethnographic research in domiciliary care

A research team is interested in the impacts on the experiences of service users with dementia associated with recent cuts to publicly-funded domiciliary care services.

In addition to interviews with service users, family members, and domiciliary care workers, the research team is proposing an extended period of ethnographic research. This will involve a researcher living with a service user who is receiving domiciliary care services, alongside the service user's close family members, in their own home. The researcher will spend all day with the family, for a period of one month, accompanying the service user in each and every aspect of her daily routine.

The researcher will ensure that consent is obtained from the service user and family members at the start of the research and will also gain consent from the domiciliary care workers who visit the home within this period.

In thinking through the ethical justification for this research, the following considerations would be taken into account:

From a libertarian standpoint: The researcher should be free to undertake this research, and this right to conduct such an inquiry should be protected, regardless of how methodologically robust this component of the study is. Whilst the libertarian approach recognises that obtaining free, individual consent from all participants is a well-recognised and ethically appropriate way of ensuring free participation in the research, the libertarian expresses concern that consent is not being sought repeatedly throughout the month-long period – both to ensure that the participants remain happy to continue to participate, but also, as the dynamic of home life changes, to ensure that this agreement is freely given and not taken for granted as the researcher becomes embedded in the everyday aspects of daily, family life. The libertarian is also uncertain about whether the service user with dementia will be able to give consent to participate, due to her level of cognitive impairment, and recommends that a service user with more mild dementia is recruited into the study.

From a paternalistic standpoint: The long duration of the observations, and the fact that these will be taking place around the clock without any respite for the service user or her family, are ethically concerning to the paternalist. The paternalist identifies that distress is likely to occur from having a stranger living alongside a person with dementia who might be particularly confused about what is going on, and that this distress will be maximised when the researcher accompanies the person into the private spaces of the home, such as her bedroom. The paternalist judges that observations of these kinds will exceed the 'minimal risk of harm' threshold that this approach endorses to judge the ethical permissibility of the research. The paternalist takes the view that the ethnographic research could be permitted to proceed, but only if the observations take place in a less intensive manner, occurring only at the precise time when the domiciliary care worker is visiting the family home, and not taking place in the home's bedrooms or bathrooms.

From a utilitarian standpoint: The utilitarian recognises that the intense, continuous observations that the researcher is proposing could be distressing for the service user and her family. The utilitarian is also concerned about the level of risk of harm that the researcher might be exposed to in living alongside the family for this length of time. In contrast to the

two other ethical positions, the utilitarian is also unsure about the scientific value of including an ethnographic component to the research alongside the interviews that are being proposed. A more detailed justification of why observations of these kinds are being used to shed light on service user experiences, as well as clarification on how these data will usefully function to improve practice or policy in domiciliary care service delivery, is sought in order to inform the overall harm/benefit calculation.

3. ETHICAL PRINCIPLES FOR SOCIAL CARE RESEARCH

From moral theories to research ethics principles

The three theoretical arguments outlined in the previous section provide an overarching approach to thinking about the ethical justification of social care research. Their justification depends on capturing the nature of a broader ethical requirement to articulate what 'doing good' in the world consists in, whether this be understood in terms of preserving freedoms; minimising harms; or by maximising utility. It is quite possible that the reader of this Review will feel intuitively inclined towards one of these approaches, rather than the others, and this might reflect their ethical views about right and wrong more generally. Alternatively, and potentially more likely, the reader might think that aspects of each approach capture ethical considerations that are relevant to making an ethical judgement about social care research, but that it is not as simple a matter as selecting one over the other.

Within research ethics scholarship more generally, the approach has aligned itself with this second interpretation, whereby each theoretical approach highlights ethical values that should be drawn upon to support an overarching judgement about the ethical permissibility of a particular research study that involves human participants. This has led research ethicists, and organisations with responsibility for research governance more generally, to attempt to identify a set of 'mid-level' ethical principles that can be drawn upon to determine whether a piece of research is allowed to proceed (or not) on ethical grounds.

An overview of ethical frameworks for research

Typically, research ethics principles have been articulated within overarching ethical frameworks for research, informed by input from ethicists, researchers, and representatives from service user and other special interest groups.

Before proceeding further, it is important to begin by differentiating between two different kinds of ethical frameworks in the research context. One ethical framework is concerned with the ethical principles that specify how an overarching governance framework to oversee the ethical review of research should be designed, and how it should function. For example, within a governance framework that endorses a research ethics committee system, the ethical principles within this 'ethical governance of research' framework might incorporate such values as independence, openness, representation, and efficiency (Sheehan et al. 2014). The second kind of ethical framework – which is the one that interests us here – is an 'ethical practice of research' framework. These frameworks are concerned with specifying the ethical principles that ought to guide the ethical design and conduct of research activities themselves (regardless of which research ethics governance framework is in place).

For the most part, however, those ethical frameworks to guide the ethical conduct of research practice advance a number of ethical principles that are recognised as necessary to consider within medical research studies, not social care research studies. International and national policies for medical research ethics include the Declaration of Helsinki[2] (developed by the World Medical Association, and now in its 8th edition), the Belmont Report[3] (developed by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research in the USA), and the International

[2] www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/

[3] www.hhs.gov/ohrp/regulations-and-policy/belmont-report/index.html

Ethical Guidelines for Health-related Research Involving Humans[4] (developed by the Council for International Organizations of Medical Sciences (CIOMS)).

Recognising that non-health related research involving human participants had been largely neglected by bodies such as these, concerted efforts have been made in the UK by research councils in the social sciences, and by learned societies, to produce similar frameworks of ethical principles for the conduct of social research. Given that a large part of social care research will be social scientific in nature, these frameworks are likely to be of more direct use to the social care research community in the UK and elsewhere.

Perhaps the two most important ethical frameworks that will be of relevance to the conduct of social care research are the Economic and Social Research Council's (ESRC) Framework for Research Ethics[5] (2015) and the Academy of Social Sciences' (AcSS) Generic Ethics Principles for Social Science Research[6] (2015). Boxes 2 and 3 summarise the two sets of principles that are put forward in each of these frameworks.

Box 2: The Economic and Social Research Council's 'Framework for Research Ethics', 6 key principles of ethical research

1. Research participants should take part voluntarily, free from any coercion or undue influence, and their rights, dignity and (when possible) autonomy should be respected and appropriately protected.
2. Research should be worthwhile and provide value that outweighs any risk or harm. Researchers should aim to maximise the benefit of the research and minimise potential risk of harm to participants and researchers. All potential risk and harm should be mitigated by robust precautions.
3. Research staff and participants should be given appropriate information about the purpose, methods and intended uses of the research, what their participation in the research entails and what risks and benefits, if any, are involved.
4. Individual research participant and group preferences regarding anonymity should be respected and participant requirements concerning the confidential nature of information and personal data should be respected.
5. Research should be designed, reviewed and undertaken to ensure recognised standards of integrity are met, and quality and transparency are assured.
6. The independence of research should be clear, and any conflicts of interest or partiality should be explicit.

Box 3: The Academy of Social Sciences' 'Generic Ethics Principles for Social Science Research'

1. Social science is fundamental to a democratic society and should be inclusive of different interests, values, funders, methods and perspectives.
2. All social science should respect the privacy, autonomy, diversity, values, and dignity of individuals, groups and communities.
3. All social science should be conducted with integrity throughout, employing the most appropriate methods for the research purpose.
4. All social scientists should act with regard to their social responsibilities in conducting and disseminating their research.
5. All social science should aim to maximise benefit and minimise harm.

[4] https://cioms.ch/shop/product/international-ethical-guidelines-for-health-related-research-involving-humans/

[5] https://esrc.ukri.org/funding/guidance-for-applicants/research-ethics/

[6] www.acss.org.uk/developing-generic-ethics-principles-social-science/research-ethics-sub-section-site-map/

Both of these frameworks identify ethical considerations for the conduct of social science research that connect back closely to the overarching theoretical approaches identified in the previous section. These principles can be usefully distilled down to three overarching principles, which are outlined below. Whilst these principles will not resolve all ethical uncertainties, and residual ethical issues will prevail even when these principles are taken into account (as will be discussed in the next section), social care researchers can usefully draw on these principles in the process of designing their methodological protocols.

Principle 1: Respect for persons

The principle of respect for persons focuses attention on what is owed to research participants who are considered for enrolment into a social care research study. The notion of 'respect' captures an overarching ethical requirement to treat people in a particular way, given their moral status as a human being. This status accords recognition of the person's unique, individual value and dignity. Typically, this principle requires the potential research participants to be recognised as someone who is autonomous (able to formulate a life of value to him/her) and free (able to pursue a life of value of him/herself), and that his/her dignity and privacy need to be respected in the pursuit of these life goals and activities. This principle can be helpfully divided into two sub-principles.

Respect for personal autonomy. As an autonomous person, a researcher is required to ensure that the person's participation in a research study is one that is made by the research participant him/herself. The idea that a participant ought to make a free, personal choice about whether to participate in a research study focuses primary attention on the process of obtaining valid consent.

Valid consent is built upon three components: information, competence/capacity, and voluntariness. An informed consent is one that the person gives based on all the relevant information concerning the research activity. Detailed information sheets that outline all the research procedures and the positive and negative aspects of involvement are critical to obtaining informed consent. It is also a requirement of this principle that the information is not just told to the person, but also that the person understands the information they are given. Thus, careful attention needs to be paid to how the information is conveyed to the participant. This might include conveying the information in a non-written format, or in an easy-read format, and is likely to require time being allocated for the potential participant to process the information and potentially ask follow-up questions, in light of any concerns they have about the information they have been provided with. If the research procedures are complex, or the person is being invited to participate in a study with a number of different components, separate consent procedures ought to be deployed.

A written consent form provides an evidential record that participants have been fully informed about the nature of their participation. When study participation takes place over a long period of time, it will be important to ensure that the person remains aware of what they have given consent to, and that this remains valid (i.e. the person continues to agree to remain a participant in the study). This is likely, in social care research studies, to support a form of 'process consent' (Dewing 2007) to be adopted. Continually re-informing the participant about the nature of their continued participation will be an integral feature of this process.

Valid consent can only be obtained by someone who has the mental ability (or capacity) to give it. People who are not able to make autonomous decisions about their research participation are not respected if it is merely presumed that they would otherwise choose to participate. Moreover, the rationale for including people who lack mental capacity is weaker in the context of research participation because it is unlikely that these people will benefit directly from being enrolled into research. This criterion of valid consent requires a social care researcher to consider whether it is likely that any research participants might lack the mental capacity to participate in the research. If so, robust capacity assessment procedures need to be in place as part of the study enrolment process. There is a residual question that arises here; if valid consent is the ethical crux for ensuring that the principle of respect for personal autonomy is maintained, can it ever be justified to undertake social care research involving people who lack mental capacity? This question will be addressed in the next section.

Finally, valid consent needs to be given freely, without the potential participant experiencing any actual or perceived coercion. In other words,

the person's choice must be a voluntary one: any pressure to participate, coming from any source, may well invalidate the consent obtained.

In the context of social care research, there is always a potential risk that social care users, particularly those living in institutional care settings, will associate a researcher approaching them to participate in a research study as an authority figure that they are required to go along with. Alternatively, service users might interpret the invitation to participate to be linked in some way to the current care arrangements that they receive.

There are some practical steps in the recruitment process that social care researchers can take to reduce this perceived coercion. One step is to work closely with, and alongside, the user's caregivers to engage the person with the enrolment process. For example, the initial approach about the research project could be made by a care home manager, or the person's main care worker. The second step is to separate the enrolment process into a distinct two-stage process. In the first phase, the person is provided with initial information about the study (perhaps, again, by a care worker), and it is up to them to decide to make contact with the researchers, if they are interested in finding out more. The second stage would then involve a meeting between the service user and the researcher in order to provide full information about the study, and to complete the formal process of obtaining consent.

Respect for privacy and confidentiality. In order to safeguard people's dignity and to enable them to pursue their own autonomous life plans, there is an additional ethical duty to respect a person's private space and personal information. Privacy involves the safeguarding of a 'zone of personal space' around the person that will typically have both a geographical (surrounding the person's body) and a symbolic component (identified, by the person, as being of special personal significance and therefore worthy of additional respect by others). The symbolic component of privacy explains why we see a person entering another person's bedroom, or rifling through a person's affects or correspondence, as ethically problematic.

In social care research, the demands of this sub-principle will be particularly significant because of the complex relationship between the management of private and public spaces in social care settings. Social care researchers will typically be seeking access to private spaces (the different rooms of a care home; the person's own home; etc.) and will need to negotiate the demands of privacy carefully, and make careful judgments about which private spaces it would be appropriate for them to access in order to carry out their research, and how they will negotiate access to these spaces.

Confidentiality refers to the informational dimensions of privacy, and respect for confidentiality involves respect for personal information. In the social care research context, confidentiality will most commonly arise as an issue in a number of ways. First, as part of the research, the researchers might seek to access confidential social care records (e.g. care notes kept in a nursing home). There is a clear ethical expectation that researchers will not be allowed access to these notes, unless the person whose information the notes refer to has given explicit consent for them to be consulted. Secondly, in the conduct of the research, data will be collected that ought to be treated as being potentially confidential because of what it denotes. In so far as the data concerns personal and identifiable information, then it must be treated as confidential, and used only for the specific (research) purposes that it has been collected, and for which permission has been granted. Finally, in reporting the research data, there is a possibility that this will be made public in ways that render the different participants identifiable. Respect for confidentiality requires that the data remain anonymous, even in the detailed, public reporting of the research outcomes.

Principle 2: Maximising benefits and minimising harms

The second principle for the ethical conduct of social care research involves ensuring that there is a positive balance between the benefits and harms that will accrue from the research study being undertaken. Unlike the first principle, which was concerned with ethical obligations that are grounded in what is owed – intrinsically – to a person, the second principle is concerned with maximising welfare-related consequences of the research taking place, or not. In this sense, the people who experience benefits or harms are ethically significant only because they are the bearers of these beneficial or harmful outcomes, not because of what is owed to them personally as individuals.

With regards to the benefits of the research, there are two main questions to consider. The first is: what benefits are likely to result from undertaking this research? If there are no identifiable benefits either to the individuals involved or to society more generally, or these benefits of different kinds are recognised as being weak or tenuous, then the burdens associated with participation in research are likely to lead to this principle being violated if the research goes ahead. Care is needed here, however. For example, a single study might offer limited direct benefits, but be part of a wider programme of research that is beneficial overall (as would be the case in a pilot study or 'proof of concept' study).

The fact that each social care research study is part of a broader trajectory of research enquiry that aims to accrue benefits to society through knowledge acquisition needs to be considered as part of a full account of the benefits that a research team is able to provide about the utility of their planned research activities. For this reason, the potential benefits associated with the research study will be determined largely by examining its methodological quality. This will involve scrutinising the study rationale, to ensure that the research question is novel, justifiable, and likely to lead to the development of new knowledge in ways that support the ongoing development of social care practice. The methods will need to be examined carefully to ensure that they are best placed to answer the research question. Attention will also be paid to the study outcomes and dissemination strategy to ensure that the potential benefits of the research study are realised to the greatest possible extent. Internal and external peer review is likely to play an important role in determining whether the research being proposed will give rise to benefits for the social care community, and whether the study has been designed in a way that is likely to maximise these potential benefits.

In considering the potential study benefits, the second question to consider is: will participation in the study lead to direct benefits to the participants themselves? There are two common ways in which such benefits might accrue. First, there might be direct benefits to the research participants if the study intends to trial a new social care intervention that will be provided to them after the completion of the study, if the research concludes that this intervention is more effective than the standard of care adopted previously. However, given that the provision of social care interventions (through established funding mechanisms) is likely to deviate from the research into them, it may not be clear whether this intervention will actually be made available to research participants after the completion of the study. And, of course, the study might show that the new social care intervention being tested is no more effective than other interventions – meaning that no additional benefits accrue at all, except through the value of obtaining knowledge about what does not work.

Second, there may be indirect benefits associated with research participation. This phenomenon is discussed particularly in qualitative social science research in social care, the argument could be made that participants will gain value about sharing their experiences or perspectives about the social care services they receive, or other aspects of their daily lives, in ways that provide a benefit to them. Sometimes, in the social care context, this claim is presented as being even stronger due to the fact that social care services are sometimes poorly responsive to service users' views and insights about their needs and the quality of the care they receive. Whilst these indirect benefits are potentially present, they are unlikely to weigh very heavily in the benefits-to-harms calculation, and they are clearly not the kind of benefits that can provide an overarching justification for the research itself to proceed (as opposed to increasing opportunities for people who receive services to have the chance to share their views and experiences as a standard part of social care practice).

With regards to the harms associated with social care research, there is no doubt that these are less significant than the kinds of harms that can arise through participation in some medical research studies. As Dewing (2007) has evocatively claimed when contrasting medical research with social scientific research: "[humanities and social science] researchers do nothing that begins to compare with injecting someone with potentially toxic green stuff that cannot be neutralised or rapidly eliminated from their body if something goes wrong". This is clearly correct. However, notwithstanding this qualification, it is still important to consider the range of harms that might accrue through the process of research participation.

One form of potential harms that could arise through social care research participation concerns the evaluation of novel social care

interventions. The new service or technology could be ineffective and/or be distressing for the person concerned. It could also have unintended, negative side effects that cause harm to the person using it. Another form of harm is the burden associated with participation in empirical social research into a social care service setting. If the person is used to a particular daily routine, a research activity could disrupt this pattern, causing potentially quite significant distress. This is especially likely to be the case if the person has dementia, or an intellectual or developmental disability. Also, in qualitative research in social care, the requirements for a person to recount or describe challenging personal experiences could be experienced negatively, leading to further harms being experienced. Finally, there are a range of reputational harms that could be suffered by social care professionals or managers if a research study reveals poor care practice, leading to a longer-term change in social care delivery in ways that threaten these individuals' professional status or job security. Note of course that such harms could be said to be permissible once appropriately balanced against the value of obtaining knowledge of the existence of poor practice. Harms that could be experienced by researchers in conducting research activities alone in people's private homes need also to be recognised in this context.

This has not been an exhaustive list of potential harms. An overarching duty on social care researchers will be to predict, identify, and pre-emptively lower the risk of these harms occurring. This may be done through, for example, making careful alterations to the research methods adopted, by offering additional forms of support to research participants, or by establishing safety protocols for lone working.

In order to satisfy the requirements of this second principle, the overarching responsibility of social care researchers is to:

- maximise the potential benefits that could accrue through the conduct of the research;
- minimise any foreseeable harms that could arise; and
- be satisfied that the balance of benefits to harms is favourable overall, supporting the research to proceed on ethical grounds.

Principle 3: Fair conduct in research

The final ethical social care research principle is concerned with meeting justice requirements within the research endeavour. As a set of practical ethical considerations for social care researchers, justice can be understood in a number of ways here.

First, justice demands that social care researchers attend carefully to whose social care needs are being foregrounded in making research priority decisions. Have certain sub-groups of social care users been arbitrarily excluded from the sampling decisions, or have a particular sub-set of problems been neglected in deciding which research questions ought to be prioritised? In the social care context, which is closely aligned with the provision of services to a wide range of people with health and social care needs, the overarching concern (often present in medical research) that groups of so-called 'vulnerable populations' are excluded from participating in research, is unlikely to be present as a major issue. Instead, however, the concern could be orientated towards the opposite concern: that certain groups that comprise relatively small numbers of people, but who have highly specific social care needs, could be over-represented in research, finding themselves constantly under the gaze of researchers who seek to study their needs and the services that could best meet them.

Second, fair conduct in research also requires attention to issues of distributive justice. This requires social care researchers to consider carefully the distribution of risks, burdens and potential benefits that are likely to accrue in the research process. There are a number of issues to consider here. One is whether certain risks borne by those participating in the research study will be addressed by benefits that the same group of people will foreseeably receive. If there is no clear pathway from those who provided the data to those who will benefit, then it looks like the research participants will bear an unjust proportion of the risks for limited benefits. This could particularly be an issue in international social care research, where research data collected outside of the UK is used to inform practice and policy developments in the UK, but result in no manifest improvements to the lives of those people who participated in the host country.

Another issue concerning distributive justice could present itself in how the study recruitment process is devised. It is possible that groups of individuals could be exploited (or unfairly taken advantage of) in order to facilitate the research taking place (Hughes et al. 2010). For example, it might be easier to recruit some social service users or social care workers in more deprived parts of the country than in other wealthier parts, particularly if the researchers are proposing to offer a financial incentive for participation in the research. In this situation, justice might potentially point towards offering calibrated amounts of financial payments, depending on the person's location.

More broadly, offering a financial incentive could function to encourage people to participate in the research study, due to their unjust social and economic background conditions, in a situation where the research team reap the benefits of this recruitment strategy, whilst these participants are not fairly rewarded for the degree of time or burden they expose themselves to in the research activity.

The fair conduct of social care research involves proactively engaging with these questions of distributive justice. In particular, social care researchers need to consider whether they are arbitrarily excluding various groups or people from the research design for convenience reasons, when these groups could benefit equally from their inclusion in the research. Researchers also need to ensure that the spectrum of benefits and burdens are reasonably distributed between research participants, and between themselves and the participants, so as to attend to any objections that the researchers are exploiting certain participants in the pursuit of the production of new knowledge.

Interpreting and balancing principles

In this section, three main ethical principles that can be drawn upon by social care researchers to steward the design of their research studies in ethically defensible ways have been outlined. These principles will need to be attended to carefully and thoughtfully in the development of a social care research protocol. They will certainly not function as an algorithm for the production of ethically defensible research, nor as a tick-box exercise to ensure that the relevant ethical considerations have been taken into account in a linear and definitive way.

In applying these principles to social care research, researchers need to address two main questions:

1. How should these ethical principles be applied to the specific research activities that are planned?
2. How should any conflict between the requirements of these ethical principles, as it presents itself in the study design, be thought through and addressed?

Engaging with these questions satisfactorily will likely present social care researchers with a distinctive range of ethical issues that they will have to attend to in the study design phase of their research. Once again, there will be no correct or straightforward answer to the resolution of these issues. Sound ethical reasoning that is tailored carefully to the specific context of the research activity – its rationale, aims, and methods – will be necessary.

4. THINKING THROUGH PRACTICAL ETHICAL ISSUES IN SOCIAL CARE RESEARCH

As suggested at the end of the last section, the ethical principles identified will not always be straightforward to apply to a specific research proposal, and they will commonly come into conflict with each other. This is an unavoidable reality of conducting social care research. The ethical issues that social care researchers face accordingly need to be attended to carefully in the process of designing their research studies.

In this section, a number of commonly occurring ethical issues in social care research will be outlined and discussed, drawn from my own experiences of being involved in designing social care research, and reviewing ethics applications for social care research projects, over the last decade. The aim of this section will not be to settle these issues in any substantive sense, but rather to show how those undertaking social care research might approach the issues, and reason them through, in light of the particularities of their specific research plans.

Involving adults who lack capacity to consent in social care research

Social care services are often established precisely to offer care and support to adults and children who have physical and cognitive impairments. Social care research that focuses on the services or experiences of adults with dementia, intellectual disabilities, or mental health difficulties means that it is possible that some of these individuals will lack the mental capacity to give valid consent to participate in research studies of these kinds.

Is it ethically justifiable to recruit adults who lack the capacity to consent to a research study to be included as participants in this study? Consider the following research study:

Box 4: Survey research on personal budgets

A university researcher has designed a study that will use survey methods to examine the effectiveness of personal budgets for adults with disabilities within a local authority. The aim of the study is to examine whether personal budgets have led to improvements in the quality of support provided to these adults. The survey includes questions on the adults' support arrangements under the personal budget system, and their attitudes towards these arrangements.

The researcher intends to distribute the survey through the local authority. The local authority will send a copy of the survey to all adults in receipt of a personal budget. The researcher and local authority have agreed that those adults identified as lacking capacity will be pre-identified using information held by the local authority. This is to ensure that those adults who have been identified as lacking the capacity to consent receive a different copy of the information sheet designed for their primary carers. The information sheet sent out to those providing care to adults lacking the capacity to consent indicates that the carer should assist the person lacking capacity to complete the survey, if they are unable to do so for themselves.

This study poses a number of questions concerning the involvement of people lacking capacity to consent. These include:

1. Should the researcher restrict the study to only include adults with disabilities who receive personal budgets and who are assessed as being able to give consent to participate in the survey study?
2. Has the assessment of capacity been undertaken in a reasonable way, and is the recruitment process likely to arbitrarily lead to the exclusion of some adults with disabilities?
3. Has the survey method been altered appropriately for the involvement of adults lacking capacity?

With regards to the first question, the involvement of people who lack capacity is a question that clearly reveals a conflict between the guiding ethical principles. From the perspective of the requirement to respect persons, the fact that the person lacks the capacity for autonomous choice points immediately towards excluding the person from research. However, the other two principles appear to point towards the opposite conclusion. If the research has been designed carefully to maximise the potential for the data collected to lead to direct benefits for people with more severe disabilities, and the harms that they will be exposed to in the research are minimised, then the study looks to be ethically defensible. Moreover, from the standpoint of the third principle, justice would appear to demand that the potential benefits from valuable research can also accrue for those who are vulnerable, or unable to fully consent to participate.

For most issues of this kind, it would be up to the social care researcher to make a case for why the study ought to involve people who lack mental capacity. In international research ethics guidelines, the involvement of so-called 'vulnerable groups' is justified by taking steps that include (i) capping the permissible harm threshold at a low level, (ii) involving surrogate consent processes that can capture the likely views of the people lacking capacity, and (iii) justifying the activity by reference to the specific needs or interests of the people lacking capacity themselves. Interestingly, however, because the issues presented here have been viewed as being so important to people in society more generally, the government has included research participation in its overarching legal framework for regulating decision-making capacity in health and welfare settings – the Mental Capacity Act 2005 (MCA) in England and Wales. This means that social care researchers are not able to offer a distinctively ethical rationale for the recruitment of adults lacking capacity. Instead, they must outline how they will adhere to the specific requirements of this law, and the research ethics committee's role (for which they have been specially trained)

is to ascertain that the MCA has been interpreted and applied correctly. Further details about the requirements of the MCA in the research context, and a link to a free, online training module, can be found here: www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/mental-capacity-act/

In the study outlined in Box 5, these requirements would involve attending to a number of issues. First, the researcher would need to demonstrate that data of equal value could not be obtained by limiting the study to people who have capacity to consent. This will require the researcher to show that the issue (personal budgets) are unique in some way to

Box 5: Requirements of the Mental Capacity Act 2005 for the recruitment of adults lacking capacity to consent (LCC) into social care research[1]

1. The research must be connected to the impairing condition that means an adult lacks the capacity to give consent, or to the care/treatment of that condition
2. There must be reasonable grounds for believing that research of comparable effectiveness could not be carried out if the project is confined to adults with capacity. (Designed to prevent 'convenience sampling')
3. The research must have the potential to:
   - benefit participants without imposing a disproportionate burden, OR
   - benefit others with the same/similar impairing condition, IF the risk to the participant is negligible, AND the research will not be unduly invasive or interfere significantly with participants' freedom of action or privacy
4. The researcher must identify a 'personal consultee' (PC) who is
   - not connected with the research project, and
   - (i) engaged in caring for the participant, (ii) interested in his welfare (but not in a professional capacity or for remuneration), (iii) has been previously named by the adult LCC, or (iv) has been appointed by a Lasting Power of Attorney, and
   - is willing to be consulted
5. The researcher must then:
   - provide the PC with information about the project
   - ensure that the PC can give advice about what the adult LCC's wishes, feelings and values would be in relation to being involved in the project
6. If the PC believes that the person's previous wishes and values would suggest he participates, the PC can make this declaration. However, this is strictly a consultation process and so it is ultimately up the researcher to decide whether that person is recruited into the study. Note that, under the MCA, no person can give consent/assent on behalf of any adult who lacks capacity in relation to a decision to participate in research.
7. For situations in which a PC cannot be identified, or the identified PC is unwilling to fulfil the role, a 'nominated consultee' (NC) should be identified
8. The NC must be:
   - person who cares for the proposed participant, or is interested in his/her welfare, in a professional or paid capacity (e.g. the participant's key worker in a care home or a GP), and
   - unconnected to the research
9. The NC is expected to fulfil the same role as the PC

[1] Note that these requirements, and the scope of the Mental Capacity Act 2005's research provisions, do not extend to the clinical trials of investigational medicinal products, which have been subject to separate regulations under European law. All social care research will, however, come under the scope of this regulatory framework. This information is correct as of May 2020. A forthcoming revision to the Mental Capacity Act 2005's statutory Code of Practice is likely to refine how to enact the specific legal requirements of conducting social care research involving adults lacking the capacity to give consent to participate. It is advisable for social care researchers to ensure that they have engaged with the most up-to-date version of this Code of Practice in preparing their research projects involving this group of adults.

the group of people with disabilities who are more severely disabled (and hence more likely to lack capacity), and therefore that the research would be impossible to meet its objectives without their involvement. It is not sufficient to argue that the research data would be better, or more complete, with a more expansive sample that includes people lacking capacity. This is because the MCA's starting point for research activities involving adults lacking capacity is that these adults should be excluded from participating, unless the research objectives demand their inclusion.

There are also additional ethical and legal concerns presented by this study, in light of these requirements. There has been no decision-specific attempt to assess each individual's mental capacity, as demanded by the requirements of the MCA. No personal consultee has been identified in the research protocol, with a carer being used to fill in the survey on behalf of the person lacking capacity. This methodological step also raises questions about the possibility of the study giving rise to meaningful benefits. Why think, for example, that another person would be able to give an accurate account of the person lacking capacity's subjective experiences relating to personal budgets? Indeed, more generally, social care researchers need to think carefully about how they can capture meaningful qualitative or quantitative data from people who lack capacity (through survey participation or involvement in a semi-structured interview) when they have also judged that the person is unable to understand why they are even being approached to take part in the research at all.

Adopting covert research methods

A second ethical issue can arise when the researcher favours adopting a particular approach to collecting their research data. Consider the study outlined in Box 6.

Here, adopting covert research methods appears to involve the requirement to respect persons conflicting with the requirement to maximise benefits and minimise harms. Not informing any of the individuals who will fall under the researcher's 'gaze' means that they cannot choose not to be involved in the study. It is for this reason that the International Sociological Association's Code of Ethics (2001) states that "[t]he consent of research subjects and informants should be obtained in advance.

Box 6: Covert ethnographic research in a care home

A social care researcher is interested in concerns raised by the social care regulator that contact between care staff and residents in care homes is not supportive of a person-centred approach to realising good care outcomes, being too rigidly focused on the completion of a minimal set of personal care tasks.

The researcher intends to examine how care assistant-resident interactions take place in the home, and the explanatory factors that might underpin the interactions that occur. She intends to seek employment in a care home and conduct covert participatory observation research at the same time as carrying out her tasks as a care assistant. She does not intend to inform the care home provider, the manager, the care staff, or the residents that she will be conducting covert observations alongside her formal employment role on the basis that this will bias her data.

Covert research should be avoided in principle, unless it is the only method by which information can be gathered, and/or when access to the usual sources of information is obstructed by those in power."

On the other hand, the researcher is likely, in this case, to be able to make a strong case that the data collected will be of no value if explicit permissions are sought from all those working and living in the care home. This is likely to be because a sufficient sample size would not be possible to obtain, given the research objectives, or because, if the staff and managers are fully informed of the study's objectives, there is a strong likelihood that they would change their behaviour in ways that would not lead to an accurate account of care home interactions being obtained. And, the social care researcher, might argue this comes at an ethical cost to the legitimacy of the research; the potential benefit of discovering how care home interactions are handled, and why this is the case, will not be realised, preventing potential improvements in care practice being realised for care home residents living in the very environments in which the research will be undertaken.

In thinking about the ethical trade-offs involved in the conduct of covert research, the researcher might also take steps to reduce the wrongdoing associated with failing to respect people living and working in the care home. In this sense, the researcher would be attempting to limit the 'moral damage' (Molewijk et al. 2008, Spronk et al. 2017) associated with the trade-off that needs to be made between the two competing ethical principles. 'Moral damage' refers here to the unavoidable ethical wrongdoing that occurs when a genuine ethical dilemma needs to be resolved one way or the other. Potential ways of doing this might include attending to how participants could be fully and transparently informed about the covert research that was undertaken, after the completion of the study, and provided with a clear rationale for why this took place and what steps the researcher has taken to make sure that the data collected will be used in a reasonable and confidential manner.

Safeguarding participants and disclosing confidential information

A third issue that can arise in the context of social care research is a perceived need to breach the strict confidentiality requirements that are set in place by the sub-principle of 'respect for the person's privacy', on the basis of preventing harm to the participant or other people. Social care researchers are often well-versed in safeguarding requirements, given the careful attention that is paid to this priority in social care policy and practice.

It is important to recognise that social care researchers are not bound by the same professional requirements as those who work in social care practice when they are engaged in a research role, and this is the case even if they also happen to be social care practitioners as well as researchers. However, safeguarding issues that present themselves in a research context will still need to be thought through, and this will again involve a balancing of competing research ethics principles. Once again, it looks like there is a dilemma that presents itself here in the requirement to respect the person and the requirement to minimise harms or risks that emerge through the research process (even if the harm that is identified is not directly connected to the research activity itself).

Consider the following study, in Box 7. In this situation, the researchers have decided that the degree of harm facing the research participant outweighs the requirement to respect the promise made to the participant to keep the interview data confidential. Given the serious nature of the harm, it looks like a clear ethical case could be made to act in this way. However, following this course of action does necessarily involve disrespecting the participant. Again, attention should focus here on limiting the 'moral damage' in how this ethical trade-off has been made.

Box 7: Investigating social worker responses to risk in adult safeguarding cases

A research team have received funding that seeks to examine the decisions made by social workers to intervene in the lives of adults who are identified at being at raised risk of abuse.

As part of the research, the team is carrying out detailed, narrative interviews with those adults who have received social worker input as part of identified risks posed by people close to them. In one interview, a young woman reports that she has been sexually abused by her older brother for the past 5 years. When asked whether she has shared this information with the social worker, she says that she did last year, but that she didn't feel it was taken seriously and it has never been brought up in further meetings between them.

The researcher who was told this information has been deeply affected by the details shared by this female participant, and is uncertain what to do after promising, and repeatedly reassuring, her that all information shared in the research interview would be kept between them. When the researcher brings up the possibility of sharing this information with the social worker, the female participant becomes very distressed and repeatedly says, "but you promised not to tell anyone else about this." In consultation with the other members of the research team, a decision is made to report this finding to the manager of the social work team in the local authority on the grounds of the seriousness of the harm that the woman continues to face.

Two approaches to handle this situation could have been adopted to pre-emptively avoid the need to address this dilemma. First, the researcher could have been clear in the process of providing information to the participant that, whilst confidentiality will be maintained in general, this could not be guaranteed in situations where data emerged that revealed that the participant, or others, are at risk of serious harm. This would limit the 'moral damage' associated with failing to fully respect the participant, as would being transparent in the context of an interview (or other research setting) that the information being shared at that point in time raises a safeguarding issue that will need to be disclosed beyond the research encounter.

Second, the researcher could set in place a protocol that ensures that the safeguarding reporting procedure fits models of good practice. The difficulty in setting a harm threshold for disclosure, and for making appropriate situational judgements about harm, could have been better dealt with in this study if the disclosure was made to the safeguarding team, who are likely to be best placed to carry out the assessment and support the researcher in making a recommendation about what further action to take. There is a particular concern in this case about making this safeguarding report to the social work team manager, given the evidence of possible negligence on behalf of the social worker who works within that team.

Developing an equitable sampling frame

The final issue that will be discussed in this section concerns the obligations on social care researchers to ensure that equality and diversity considerations are taken into account in the development of a recruitment strategy that meets the requirements of distributive justice. There are particular challenges for social care researchers to attend to in thinking through precisely what justice demands in the context of undertaking social care research in a diverse, multi-cultural setting. Consider the case set out in Box 8.

Is this researcher's response reasonable? It is clear that there is no overarching methodological rationale for extending the sample frame in this way, and therefore doing so does not look like it would be required from the second ethical principle of maximising benefits and minimising harms. Whilst, of course, expanding the research to include a diversity of views and perspectives is likely to improve the quality of the data, the researcher's view is that the rationale for the project means that limiting the sample frame to English speakers will not invalidate the possibility of producing data that will benefit older social care users and their caregivers. Note, that this would clearly not be a reasonable or justifiable methodological approach if the research aims had explicitly focused on the perspectives of exploring care home transitions for people from the Muslim community, for example. However,

Box 8: Qualitative interview research on care home transitions decision-making for older adults

A researcher is exploring how decisions about the move from the home setting to a care home are made by family members, and what drivers lie behind this transition. The researcher intends to undertake the research in Birmingham and will recruit 40 participants to include both the older person who is moving into the care home and family members who have been involved in the transition.

A university colleague of the researcher asks why he is not intending to take steps to translate the research materials into other languages, including Urdu, Punjabi, Bengali and Somali – the languages spoken most commonly by non-English speakers in the city – as well as sign language. The colleague also suggests that the researcher should recruit research assistants from ethnic minority groups who will be able to carry out the interviews in these languages. This he says, would be a much fairer way of recognising the diverse needs and perspectives of the people living in the area where the research will be conducted.

The researcher replies that he recognises his colleague's concern. But he says that he does not have the funds to make these changes. He adds that he is satisfied that, in limiting recruitment to English speakers only, the research will still produce important novel insights into family decisions to move an older person into a care home.

given the rationale for the study, limiting the sample does not seem to seriously undermine the methodological quality of the research, and so this seems like a reasonable trade-off to make from the standpoint of the second ethical principle. If this were not the case, it would have profound implications for social care research more widely, requiring researchers to capture each and every possible perspective in order to defend the methodological validity of the work conducted.

But, is this response reasonable in light of the demands placed upon him by the third ethical principle of fair conduct in research? The answer to this question is less clear. In a socio-cultural context where a number of people are non-English speakers, the decision not to proactively take steps to engage with non-English speakers as participants in the research does look to fall foul of the complaint that this decision unfairly skews the distribution of benefits of the research away from those who do not speak English and towards those who do. It is also reasonable to think that this approach is problematically exclusionary, especially if there are grounds to think that the unique different perspectives of non-English speakers, and the implications that these perspectives have for service design and delivery, are being systematically silenced across social care research more generally.

For these reasons, the principle of fair conduct in research would, therefore, provide this researcher with a prima facie reason to think about how the potential benefits of the research could be distributed more equitably, in light of the particular circumstances of those who do not have verbal English as a first language. However, the researcher's response that he does not have the resources to enable this appears to be a practical constraint that undermines the ability to act as he ought. It is not the case, after all, that the researcher dismisses his colleague's objections, failing to feel the force of the ethical point being made.

It is important to note that the requirements of justice, as they present themselves in social care research, might not be limited to making direct changes to the research protocol, but could raise obligations for researchers to advocate for a more equitable research culture in broader terms. Aside from thinking imaginatively how the costs of translation could be met through new local partnerships with service user and cultural groups, one action that the researcher could take here, for example, is to request additional funds to ensure that the research is being undertaken in a more equitable manner. If the funder is not forthcoming with these funds, the obligation might shift to one concerned with the research raising awareness about this inequity in social care research, and campaigning for structural change within the research community that can lead to additional resources being allocated to diversity and equality concerns of this kind.

5. FACING THE RESEARCH ETHICS COMMITTEE

Up to this point, the guidance offered in this Review has been orientated towards supporting social care researchers to design the specifics of their research protocols in ways that stand up to ethical scrutiny. Equipped with the requisite principles, and aware of the various kinds of ethical issues that can arise, the idea is that social care researchers will be able to make sound ethical judgments about how to set up and carry out their studies. However, the ethical scrutiny of social care research is not something that is confined to the ongoing management of the research study by the research team themselves. Social care researchers are also held to account for the ethical conduct of their research.

The external, ethical oversight of social care research involves the use of 'research ethics committees'. All social care research must be reviewed and approved by a research ethics committee (of some kind) before it is allowed to commence. Failure to obtain approval of this kind will potentially open researchers up to legal challenges of negligence, to professional sanctions (if they are employed by a body that engages in the conduct of research), and to academic disadvantages (established academic journals and publishers will not consider manuscripts that have not obtained the requisite ethical permissions).

Why research ethics committees?

It is worth briefly considering why this external, ethical oversight of social care research has been established, and whether it is justified. After all, given the ethical learning points of the previous sections, two very different paths to ensuring the ethical conduct of social care research could be outlined:

1. An expert ethicist, knowledgeable about ethical principles for research and skilled in ethical reasoning, reviews each study and declares whether they are ethically permissible to proceed, or not.
2. The researchers, aware of the ethical principles, trained in ethical reasoning, and very knowledgeable about the precise purpose and nature of their research plans, design their study in ways that are ethically defensible, and constantly review and refine the study design throughout the entire research process as issues arise or study requirements change.

Why think, therefore, that a research ethics committee making pre-emptive decisions about whether a particular research study should be allowed to proceed is the most appropriate strategy for governing the ethics of social care research? This is precisely the argument being made currently by a number of prominent British social scientists. There is a rapidly growing body of literature that suggests that established processes for research ethics review are not justifiable when applied to empirical social research. Indeed, some authors have begun to claim that research ethics governance procedures in this context might in fact be unethical.

A number of arguments are advanced for this view (e.g. Dingwall 2008, Hammersley and Trainaou 2011). These range from the claim that

1. ethical oversight compromises social scientists' freedom of expression and the right to conduct research
2. the limited harm in social research renders ethical oversight to be unwarranted, and
3. the research ethics committee will make judgements in moralistic terms that reflect their own ethical biases and bugbears, legitimated under the guise of an ethical expertise that they do not actually possess.

There are two responses to these kinds of claims. The first is to clarify the precise normative justification for the pre-emptive ethical governance of social research, given the stake that society has in research of this kind (Sheehan et al. 2018a), and to clarify why an appropriate model of governance that does justice to this stake requires a committee approach to the giving or withholding of favourable opinions that provide a licence for the research to proceed. The second is to address the more specific concerns about how this governance framework operates, given the distinctive features of social scientific and social care research, such that it is fit for purpose.

The over-riding rationale for the pre-emptive ethical scrutiny of social care research by a research ethics committee lies in the potential for reasonable disagreement in how the necessary ethical judgements and trade-offs discussed in this report ought to be made. It is entirely feasible to think that the researcher's judgment about how these trade-offs should be made will be unacceptable to someone who disagrees – in an ethically reasonable way – with this judgment. Indeed,

> "[t]he justification of any system of social research ethics governance... is its acceptability to those who reasonably disagree about how the different ethical values relevant to making a well-reasoned judgement about the acceptability of a piece of research should be balanced" (Sheehan et al. 2018b, p.719).

In practice, a committee approach to ethical decision-making is a well-established mechanism for handling the requirement to make a decision, in a fair, procedural manner, when reasonable disagreement of precisely this type persists.

It is important, however, to ensure that the governance framework that shapes how research ethics committees' function is tailored and calibrated correctly to the social care research setting. In so far as social science and social care research give rise to less ethical issues or conflicts when compared to medical research, research ethics oversight procedures need to be nimble enough to enable the proportionate review of studies that do not raise any material ethical issues, or to adapt as new technologies, interventions, and prevailing attitudes around moral acceptability evolve. The moralising tendencies of ethics committees that concern Hammersley and Traianou (2011) need also to be addressed so that a full range of ethical considerations are attended to, in a fair and reasonable manner, in the ethics review

process, and that particular considerations that concern one or more members of the committee are not over-weighted in the review process.

Recently established, formalised review templates provide one way to guarantee that this happens – promoting procedural consistency in how research proposals are subject to a uniform process of ethical scrutiny by committee members. Another way of ensuring that all ethical considerations are given a fair and equal hearing is the appointment of a trained ethicist on a research ethics committee, tasked with ensuring that the discussions remain focused, in the right kind of way, on the ethical issues that the study raises. Finally, it is important that the composition of the ethics committee includes expertise drawn from the social care research, user, and carer communities. This can help to ensure that the ethical principles are interpreted in the right kind of way to the research methods and study design decisions made, and that these draw on carefully articulated contextual understandings of first-person perspectives on how harms and benefits are experienced by potential research participants who receive or provide social care services.

Which research ethics committee?

As Woolham (2011) outlines, there are complex intersections between multiple research governance frameworks relevant to obtaining the necessary approvals to undertake social care research in the UK. This complexity extends to research ethics governance, and the location and responsibilities of different research ethics committees. For the vast majority of social care research undertaken in England, the research ethics committees that will be tasked to review social care research studies will be convened in universities, or within the Health Research Authority's Research Ethics Service (HRA). For those studies that require 'HRA approval', a Social Care Research Ethics Committee (SCREC) operates in a way that is designed to meet the specific needs and focus of the social care research community. Box 9 outlines the kinds of research that SCREC will review. For all other social care research studies, the university that hosts the research will be tasked with providing the necessary ethical review and approvals.

All approvals for research ethics approval need to be in place before the research can proceed, and there may be other permissions required from within public and private social care provider organisations that will also need to be obtained, most of which will require ethical approval to have been obtained before these further research governance permissions are granted.

At the committee meeting: making arguments; defending judgments

Uncertainty, fear and, occasionally, frustration are common feelings that are experienced by social care researchers when facing a research ethics committee to defend the ethical robustness of their research. In order to reduce the likelihood of these negative experiences arising, it is important that social care researchers are clear about the purpose of this review and that they do not attend with erroneous expectations about what the process will require of them.

Essentially, the committee (usually through the Chair) will ask a series of questions that aim at highlighting uncertainty amongst the committee members about the ethical judgements made by the researchers. This uncertainty might relate to how the ethical principles have been interpreted by the researchers in designing the study, or relate to any concerns the committee have in how the researchers have addressed and worked through the ethical issues raised by their research protocol.

The process of engaging with the questions posed by the committee provides an important opportunity for the researchers to actively explain and defend various aspects of their methodology and research protocol, in ways that are properly responsive to the demands of the ethical principles laid out in this report. This is one reason why there is a strong argument in favour of researchers attending the committee meeting in person or over the phone. Without them being present, it is very difficult for the ethics committee to come to an all-things-considered judgement about whether the research study is built upon sound ethical foundations, because it is impossible to probe the precise reasoning that lies behind the decisions that the researchers have made.

When an ethical trade-off is required to be made in the research design, the committee will expect to hear a clear and concise ethical justification for why this trade-off is being made

Box 9: The remit of the Social Care Research Ethics Committee (SCREC)

The SCREC reviews applications involving the social care sector (e.g. in local authority, private and voluntary care settings) not suitable for review by other Health Research Authority (HRA) RECs or which cross sector boundaries. It generally expects to review the following types of study:

1. Social care studies funded by Department of Health and Social Care.
   - Research commissioned directly through the National Institute for Health Research (NIHR) Policy Research Programme[1].
   - NHS Digital studies (i.e. those to be designed by IC for implementation by Councils with Adult Social Services Responsibilities, who do not then individually need to seek additional review).
   - Studies commissioned by or through NIHR School for Social Care Research.
   - Social care studies funded through NIHR.
2. Social care research that involves people lacking capacity in England and Wales and requires approval under the Mental Capacity Act 2005. SCREC is recognised by the Secretary of State as an Appropriate Body for this purpose.
3. Social care research involving sites in England and another United Kingdom country.
4. 'Own account' research undertaken by Councils with social services responsibilities, where the Chief Investigator and/or sponsor feels there are substantial ethical issues.
5. Studies of integrated services (health and social care), provided that there is no clinical intervention involved.
6. Studies taking place in NHS settings with NHS patients where the approach uses social science or qualitative methods, provided that the research does not involve any change in treatment or clinical practice.
7. Other social care studies not suitable for review by other HRA RECs, subject to the capacity of the SCREC. This could include service user-led research.
8. Intergenerational studies in social care, where both adults and children, or families, are research participants.

SCREC does not consider any research involving clinical interventions. Such research should be reviewed by another appropriate REC within the HRA. Researchers undertaking studies using NHS organisations for recruitment or fieldwork will need to apply for HRA approval, alongside the application for REC review. HRA approval brings together the assessment of governance and legal compliance.[2] The opinion given by SCREC has the same authority as that of any other HRA REC. Such applications do not require separate review by other HRA RECs.

[1] www.nihr.ac.uk/explore-nihr/funding-programmes/policy-research.htm
[2] www.hra.nhs.uk/approvals-amendments/what-approvals-do-i-need/hra-approval

in the way that the researcher is proposing, in order to be reassured that the approach taken is sound and reasonable. Importantly, there is no pre-determined right or wrong answer to the questions posed, and participation in the discussion ought to be approached in a thoughtful and responsive manner. This is important because it is quite possible for the ethics committee to object to two opposing proposed courses of action in the research, on different ethical grounds. Consider the proposal presented by a social care researcher in Box 10.

Box 10: Paying research participants

A researcher is proposing to offer £20 in cash to all the participants who agree to take part in her social care interview study. She is uncertain, however, whether this is ethically justifiable.

In this example, it is quite possible that the research ethics committee could argue for or against the payment on a variety of different

grounds. Concern could be posed that any payment could invalidate voluntary consent on the basis that the person is being coerced into a research study that they would not otherwise agree to participate in. Alternatively, if no payment is offered, the ethics committee might raise an ethical objection to this, requiring reassurance from the researcher that she has good reason to be confident that, without offering any incentive to participate, she will be able to recruit enough people to realise and maximise the potential benefits that could accrue from the research taking place with a large sample size.

Unsurprisingly, it is quite common for the discussion between members of the research ethics committee and the researchers to become quite robust, particularly if there is a prima facie disagreement between the researcher about why, for example, a particular recruitment strategy is being employed and the objections that the committee has to this approach being adopted, on the basis of a different weighting of the relevant ethical principles. Engaging in ethical argument of this kind, however, is the sine qua non of the research ethics review process. The research ethics committee is not trying to catch the researchers out; rather they are seeking to probe the researchers' ethical justifications, and to ascertain whether these stand up to reasoned ethical scrutiny.

6. CONCLUSION

This review aimed to clarify the requirements for the ethical conduct of social care research that involves human participants and provide social care researchers with information about the overarching ethical rationales for considering the ethical permissibility of their research activities.

Practical guidance has been offered to how social care researchers ought to approach the process of obtaining ethical approval from a research ethics committee, providing tools to enable them to articulate, justify, and defend research practice and the methodological decisions made in designing specific social care research studies.

By taking into account the ethical considerations laid out in this report, I hope to have gone some way to demystifying the research ethics approval process for social care researchers.

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