ORIGINAL PAPER

Working with care leavers and young people still in care: ethical issues in the co-development of a participatory recordkeeping app

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Abstract

An important element of social research is the ethical treatment of research participants. This paper outlines the ethical issues pertaining to a study (MIRRA: Memory-Identity-Rights in Records-Access) that developed a 'participatory recordkeeping system specification' for young people in care. The research team worked with members of the cohort themselves (aged 13–17 years) and care-experienced adults. It discusses in general terms the various elements that require ethical consideration, such as informed consent, anonymity, avoiding harm, and needing to benefit the participants and their peers. It goes on to describe how such issues were approached by the team. The particular ethical measures required for the young and 'cared-for' participants are explored. These included the need to work through, first, an adult gatekeeper—a representative of each care organisation approached—and then, within the organisation, a social worker or care-giver. This greatly limited recruitment, as these adults often vetoed contact with the young people themselves. A checklist is outlined, derived from the 'Gillick Test of Competence' to assess capacity to give 'informed consent', for willing gatekeepers/carers to consider. The article then addresses how the Participant Information Sheets were developed for the young cohort, emphasising the need to do this by consulting appropriate professionals, published guidelines and the potential participants themselves. After considering the possible risks and benefits to participants, the paper concludes by suggesting that ethical issues around recruitment and participation of this cohort are complex and require much additional bureaucracy, patience and flexibility—but can be immensely rewarding.

Keywords Ethics · Informed consent · Care-experienced · Participatory recordkeeping · Inclusive research

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Introduction

An important element of undertaking research involving human beings is the ethical treatment of the 'subjects' of the research (including, in fact, whether 'subjects' is even an appropriate term). This paper outlines issues pertaining to research ethics in the context of a study (MIRRA: Memory-Identity-Rights in Records-Access) that developed a 'participatory recordkeeping system specification' for young people in care, involving both the young people themselves and those who had been in care earlier in their life.[1] The latter cohort had participated in an earlier phase of the research, which explored issues around access to their own care records, the content of those records and the lack of their own voice therein.

This paper considers the ethical dimension of the initiative—an aspect that is particularly relevant considering the sensitivity of the topic and the cohorts for whom (and, indeed, with whom) the work was undertaken. Before describing the project briefly, an outline of related research in the area of archives is given. An overview of the concept of ethics as it relates to academic research is then outlined, followed by a discussion of specific ethical issues and how these were addressed in the project. These include (but are not limited to) considerations around the sample cohort and their recruitment, facilitating informed and autonomous consent, ensuring participant well-being and the benefits of the research, both individually and in a wider context.

The MIRRA (Memory-Identity-Rights in Records-Access) project

Cognisant of the problems in social care recordkeeping from previous literature (e.g. Evans et al. 2015, 2017; Murray et al. 2008; Wilson and Golding 2016), the MIRRA group of researchers at University College London (UCL) began a programme of research that aimed to develop a better understanding of the experiences of care leavers in accessing records (see Hoyle et al. 2019, 2020 and Shepherd et al. 2020). Of interest were people's motivations for wanting access, their experiences in accessing and reading their records (often 'significant harm and pain' caused, for example, by redactions described as 'both morally and ethically reprehensible'— Hoyle et al. 2020, p. 8), and information rights, with a particular emphasis on rights to privacy, confidentiality and access to records and data (ACRCG 2016). The study concluded that young people and their families should be engaged in the creation and content of care records, and that care leavers should enjoy self-determination about what happens to those records in the longer term. At present, control is still in the gift of social care and information governance professionals.

These findings prompted a second phase of the project—the creation of an open-source specification for a more participatory digital social care recording system, and was undertaken with OLM Systems, a leading vendor of child social care systems in the UK. The aim of this phase of the project was to create a specification

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[1] A MIRRA blog discusses the project and the issues arising: https://blogs.ucl.ac.uk/mirra/.

to act as proof of concept for the development of software that will serve the needs of the child social care community. The specification is available for use by system developers and others as a roadmap for software design, acting as a basis for estimating product development costs, assessing associated risks and developing implementation schedules (Shepherd et al. 2021). Work is underway to develop a prototype app from the specification.

In addition to the software development, earlier stages of the follow-on project involved working with and collecting data from relevant stakeholders (care-experienced people, information professionals and care workers in particular). These human activities, of course, had to be approved by a university Research Ethics Committee (that of UCL in this case) which involved consideration of a number of ethical issues, not only around the conduct of the research and the well-being of the participants, but also of their understanding of the research (in order to give 'informed consent' to participate), the confidentiality of the information they gave and data sharing and storage. Their participation consisted of the following activities, both undertaken remotely (via Microsoft Teams) due to the ongoing Covid-19 pandemic:

- Two 'Knowledge Exchange' workshops to ascertain the various stakeholder requirements for the proposed system, giving priority to the care leaver perspective;
- User-testing sessions with a number of young people (aged 13–17) in care.

The ethical dimensions of these activities within the wider programme are discussed later in this paper. First, however, it offers a definition of the term 'ethics' and outlines in general terms the elements of social research which require ethical consideration. Relevant prior work by the MIRRA team (Sexton et al. 2018) is also outlined.

Ethics and the research process

A dictionary definition of 'ethics' (Merriam-Webster n.d.: online) states that the term means 'the principles of conduct governing an individual or a group …. a set of moral issues or aspects (such as rightness)', and clarifies that 'While *ethics* [original emphasis] can refer broadly to moral principles, one often sees it applied to questions of correct behavior [sic] within a relatively narrow area of activity'. Farrimond (2013, p. 12) states that 'ethical practice in social research involves consciously considering ethical values and making decisions based on them'. As with a general consideration of 'ethics', these are 'socially normative' in that 'what everyone agrees is "right" is often considered ethical'.

Issues pertaining to social research ethics have been itemised by the Social Research Association (Smith 2021) as informed consent, confidentiality and anonymity, and avoiding harm—each one being very broad and encompassing different elements. There seems to be a general agreement that research with groups

considered to be vulnerable[2] also has the ethical dimension of needing to be of bene-fit to participants themselves (Goldsmith and Skirton 2015; Kellett et al. 2010). Also emphasised with these cohorts is the ethical importance of 'inclusivity' (Frankena et al. 2019; Nind 2014). This is an approach 'conceived as research *with, by* or sometimes *for* …. In contrast to research *on* them [Nind 2014, p. 3 (original empha-sis)]. Inclusivity is typified by the practice of 'participatory research' (Morgan et al. 2015; Walmsley and Johnson's 2003) oft-cited work in the area details aspects of 'subjects' of the research become 'participants', being involved as co-designers, interviewers and data analysts, often driving the research for their own betterment.

Ethics and prior work by the MIRRA team

Prior work by the team that later developed the MIRRA project also addressed ethi-cal issues. In particular, the team examined government administrative data for edu-cation, transport, energy and health, in order to elicit stakeholder perspectives about the sharing, linking and re-use of these data (Sexton et al. 2018). The study revealed 'significant variations in data provider and researcher attitudes' (p. 1) regarding the topic of consent. It identified various factors which might account for these dispa-rate views, including organisations' approaches to data release and risk, and public perceptions and attitudes. The paper concludes by suggesting that a 'social contract' model of data sharing might be more appropriate than seeking individual consent. This model would require 'reasonable expectations about how data will be shared; … transparency about the [how] individual freedoms are respected; … governance that will give acceptable assurances, and on who is accountable for what' (p. 14).

Ethics and the MIRRA project

Terminology

Before discussing ethical issues that arose with regard to our MIRRA research, to which this paper now turns, a preliminary consideration is needed, regarding the ethical dimension of the terminology used—the 'labelling' of people in general, and that of the cohort with whom we worked (e.g. 'care leavers').

Terminology is a major consideration, both in social research and in wider soci-ety. Whilst it is impossible not to use a particular term when discussing a specific condition, situation or activity, the choice of term is very important. Mousavi et al. (2020) highlight how language can not only stigmatise people, but cause self-stig-matism and ultimately negatively affect self-determination. Although discussed with

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[2] Since the Care Act of 2014 (HMG 2014) in the UK, there has no longer been a specific definition of 'vulnerable'. Instead the Act defines people in terms of whether safeguarding duties apply to an adult who has care and support; is experiencing, or at risk of, abuse or neglect; and is unable to protect them-selves from either.

regard to 'labelling' of disabled (the authors argue for the term 'para-abled') people, inappropriate (even if unintended) terminology can be harmful, or at the very least, disrespectful, to any cohort of people. One current debate around this topic is gender-neutral language (e.g. Saguy and Williams 2019).

The MIRRA project followed inclusive or participatory terminology, as outlined above, in describing people from the cohorts contributing to the research. Whilst 'participant' is far preferable to the clinical and somewhat frosty term 'subject', we chose that of 'co-researchers' (following e.g. St John et al. 2018). This, like the term 'contributor', used frequently in the first phase of MIRRA recognised 'the relationships of mutual respect and Knowledge Exchange between academic researchers and those with lived experience' (Hoyle et al. 2020, p. 4). Finally, we preferred the descriptor 'care leaver', as advocated by the Care Leavers' Association (CLA), which defines the term as 'any adult who has spent time in care as a child (i.e. under the age of 18)' (CLA 2014: online). This broadens the definition from that in legislation (HMG 1989, 2000) which defines care leavers as previously being under Local Authority care. The CLA definition includes care provided by the voluntary or private sector (e.g. Barnardos, The Children's Society [etc.]) … [and] a wide range of accommodation' (CLA: Ibid). To avoid over-use of the term, we also use the term 'care experienced'.

Extent of 'co-researching'

'Co-researching', as the name suggests, implies an equal partnership, of pooled and complementary expertise (Williams 2020). In practice 'equality' is extremely difficult as it is the academic institution that applies for funds and academic researchers who are employed directly in the form of Research Assistants, Associates or Fellows. Remuneration for co-researchers cannot match this. Similarly, universities and other research establishments are geared to serve academics (in training, ethical standards and even links with commercial organisations and charities). Nevertheless, partnerships can, of course, be forged in terms of complementary skills and experiences.

Before discussing our work a brief acknowledgement of the work of, perhaps, the leading figure in the world of research in recordkeeping (and creating) with non-academic co-researchers, Joanne Evans (along with Gregory Rolan and other colleagues) has undertaken much work in this area. One major example is Rolan et al. (2020) account of designing an 'information infrastructure' to address the lifelong recordkeeping needs for children in care [other work by this team includes Evans and Wilson (2018); and Rolan et al. (2019)]. A series of participatory design and 'prototyping workshops' was undertaken with care leaver 'co-researchers' to explore 'participatory approaches inform the design of lifelong information systems' (p. 214). These first focussed on 'the development, and refinement of a trajectory of childhood Care [sic] experience that articulated Care relationships, activities, processes, transition points, and other events' (p. 209). The reported 'street level' perspective of the co-researchers (or 'co-designers'—the two terms being used interchangeably) 'provided insight into the meaning and effect of the records and recordkeeping'.

Later workshops considered the infrastructure (rather than the interface) of a participatory recordkeeping system. This became a 'developmental map' of how records were used at different stages of the trajectory, 'map[ping] each record type against its stakeholders and various age groups to analyze [sic] how records and recordkeeping could manifest at each of these life stages' (p. 210). Following this, a 'Personas' method was used to 'reconstruct a set of Care-related … records to use as prototype data'. This technique was used because 'research ethics constraints prevented us from using real childhood stories' (p. 211). Being 'co-researchers' allowed participants to appreciate the issues from the perspectives of those with other roles and to establish trust and rapport. It also enabled the academic researchers to question assumptions about research outcomes and communications (p. 213).

In our case, the subject and scope of the research 'was driven by the co-researchers' commitment to maximize the positive impact of the research on the experiences of future care leavers' (Hoyle et al. 2020, p. 3. See also Hoyle et al. 2019). For phase two, the University Ethics Committee advised us not to contact anyone expressing a prior wish to be involved until ethical permission had been given to begin phase two (and thus requiring aims, methods, protocols, etc., to be pre-determined). Thus, this meant that the academic team alone, for example, had to draw up initial draft consent forms for Ethics Committee approvals. However, during phase one and the seed funding work, the consent processes were discussed with co-researchers, regarding what would be documented, recorded and kept, for how long and how the information would be used (ICO 2018). Openness and continual discussions throughout were very important, as the whole premise of the research itself was to understand how care-experienced people could contribute to and control their information and voice and to have agency in the context of records. These processes are discussed further below.

In terms of the data collection and analysis, six co-researchers attended four half-day participatory workshops (for phase one) during which data were collected through collaborative exercises and activities (Ibid: p. 4). Careful decisions were taken about how to capture information and when to record, given that there was a sense from some participants that the care system had captured their voice and experiences without true consent. In addition, there was an importance in having individual private testimony and group discussions to share and validate experiences. Choices were given to participants around different forms of participation, in recognition that participants may require different avenues for self-expression and contribution. In two of the workshops, visual minutes were created (see Fig. 1). However, perhaps the most impactful research document was created at the Symposium in July 2019 when a textile plait 'weaving together individual testimonies' was created as a striking artwork and record. Each participant or a group of participants could draw or write something about their time in care to be sewn onto one of the strands of the plait (Figs. 2 and 3).[3] In addition, some brought in an object to be bound into the plait to stand as a powerful symbol of their experience in care or their

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[3] More such contributions can be seen at: https://blogs.ucl.ac.uk/mirra/.
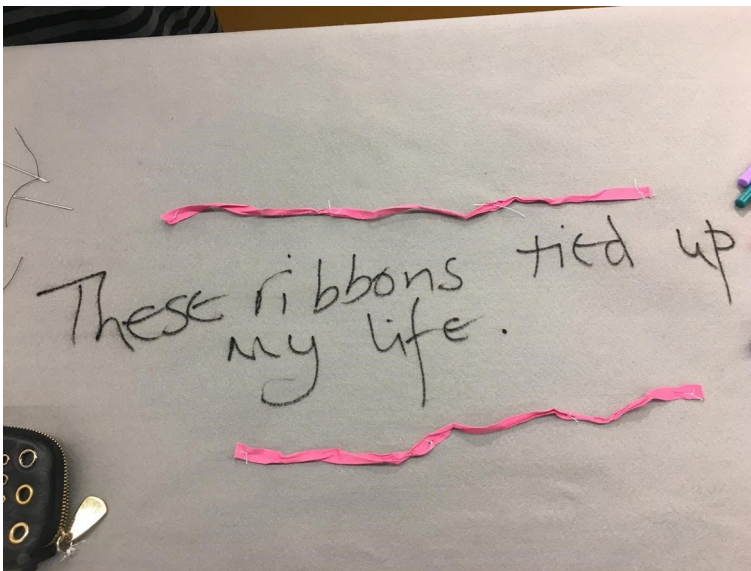
Fig. 1 Visual minutes London []
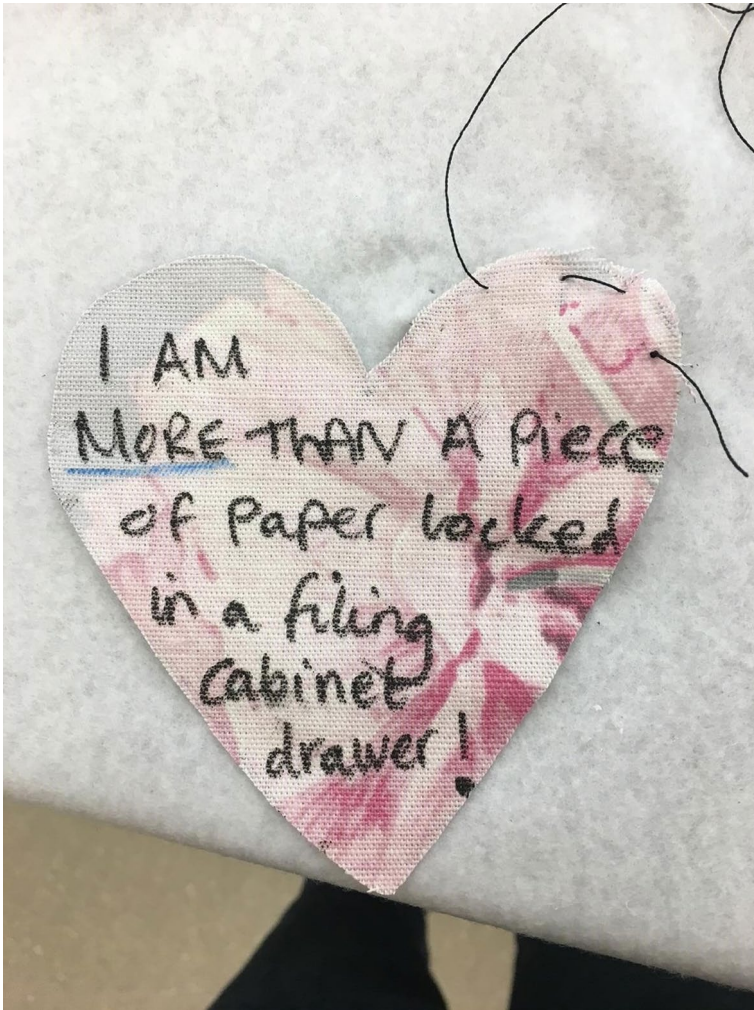

Fig. 2 Example plait contribution (1)

Fig. 3 Example plait contribution (2)

sense of their care record. The plait was co-created ahead of and then throughout the Symposium day.

The co-researchers agreed that there would be some outputs on which they would be named, and we offered opportunities for them to write and present (which was undertaken in joint conference papers). For some outputs they were happy to step back and let the academics write and be named as the authors on those outputs, although the opportunities to participate were left open.

It is worth exploring the issue of co-authorship in general, to illustrate how we did not simply 'gift' authorship to the co-researchers. Ethical guidelines (indeed, requirements) exist in this practice. Helgesson et al. (2021, p. 27), for example, suggest that 'authorship should be attributed to those who have made a substantial

contribution to the specific research leading up to the publication, even if their particular contribution is not reported in the paper'. An example is that of the British Sociological Association (BSA 2001), which states that at least two of the following contributions are required to be a named author:

(a) 'Conception or design [of the project or paper].
(b) Data collection and processing.
(c) Analysis and interpretation of the data.
(d) Writing substantial sections of the paper'.

There are also similar requirements regarding the authorship of scientific papers (see e.g. ICMJE n.d.) In the case of MIRRA, co-researchers worked on the design of both the project and papers and also were instrumental in coding and interpreting the data. As this input was, necessarily, not as comprehensive in phase two, the current paper is authored solely by the academic research team.

Informed and autonomous consent

'Informed consent' is generally considered to be composed of three elements: information provision, the understanding of that information and the autonomy afforded to the potential participant (Farrimond 2013). Cameron and Murphy (2007, p. 113) point out that valid consent requires a person to possess and understand all the appropriate information, consider the advantages and disadvantages and make a choice 'free from coercion'. Similarly, Goldsmith and Skirton (2015, p. 436) opine that 'adequate disclosure of information, freedom from coercion and capacity (or competence) to consent' are the key factors in facilitating informed consent.

Several participant cohorts may need special consideration. Younger people, adults with learning disabilities and those who speak English as a second/additional language are examples. Difficulties may be in understanding the information provided, and for the former two groups, it may also be the concept of informed choice. As discussed in-depth by Field and Behrman (2004: online), 'only those who are held competent to make autonomous decisions on their own behalf can provide informed consent'. In other words, potential recruits have to understand what is expected, what the risks and benefits are before they give consent. To this end, for the user testing phase of the MIRRA project (this follow-on phase termed MIRRA+), we created a profile to help gatekeepers choose potential participants on the basis of their likely competence. To do this, the so-called Gillick Test of competence (CQC 2018) was used. This test came about as a result of a court case (All England Law Report 1984) in which it was established that children under 16 can consent independently to medical treatment 'if they have sufficient … intelligence to fully understand what is involved … including its purpose, nature, [and] likely effects and risks' (CQC 2018: online). The 'test' has since been applied to wider applications of consent, including in the field of social science (Williams 2006). There are no specific 'test questions' to assess Gillick competency NSPCC (2020a).

Rather, recruiters need to consider several things when assessing a child's capacity to consent, including:

- Age, maturity and mental capacity;
- Understanding of the research and their role; the advantages, disadvantages, risks and implications of taking part;
- Ability to explain their reasoning and decision making.

Clearly, an assessment of any of these factors is subjective (Hunter and Pierscionek 2007). We acknowledged this in our information for gatekeepers, in case they felt we required some form of objective test. Also, the gatekeepers we used had a fairly intimate knowledge and understanding of the people in their care and were thus able to make these judgements. Considering all of these factors, the lower age of 13 was chosen because it is the age the UK Information Commissioner's Office (UK-ICO) considers that individuals (generally) have the mental capacity to consider all of the factors necessary to be able to make informed choices (ICO 2019) (the research being carried out under the jurisdiction of this body). It is also the age at which the adult care leaver cohort participants felt they could have begun to contribute substantially to their own record.

The Participant Information Sheets, and the research activities themselves, need to be clear and comprehensible. Our project was hampered by time constraints imposed by Covid and other factors, and so we relied on expertise built up in prior research with different cohorts. This earlier work had included various methods to ensure materials were written in an appropriate and appealing manner. Work we were able to build on for the project consisted of:

- Consulting existing guidelines and standards on Easy Read materials (e.g. Change People.org 2018; NHS 2017; and Cheshire and Wirral Partnership 2015)
- Liaising with carers and supporters;
- Obtaining feedback from potential participants themselves or self-advocacy groups which mirrored that of the target population;
- Following guidelines available by our university Ethics Committee literature;
- Researching how others had described their research to participants. For example, we used Prosser and Bromley's (1998) useful 'checklist' of how to use accessible language in interviews, considering that recommendations apply also to written communication. We were not able to emulate other methods we found, such as Watchman (2016), who used a pictorial information sheet, or Munford et al. (2008) who created a video about their work. Time constraints and lack of required expertise precluded these initiatives.

Participant autonomy

Considering the factors mentioned above including the Gillick Test and our choice of cohort age, we advocated, in our information sheets to guardians, a high level of autonomy for the young person in deciding participation. In this we followed

the approach generally adopted by childcare organisations (e.g. NSPCC 2020b); in government guidance (e.g. DoH 2001); and much academic literature (e.g. Masson 2004; Larcher and Hutchinson 2010). Williams (2006, p. 20) opines that this cohort should be allowed to 'speak for themselves, subject to appropriate safeguards', and Alderson and Morrow (2004) regard young people as experts on their own daily lives and, as such, capable of determining for themselves the possible benefits and risks participation may occasion.

Having stressed the need for a high level of autonomy, however, we nevertheless felt ethically bound to adopt the approach of the NSPCC (n.d., p. 7) which advises that although 'consent should be sought from young people and children … consent [should also be] obtained from a parent'. However, in an information sheet to guardians we stressed the importance of accepting the view of the young person. As the NSPCC (n.d., p. 7) states, 'a young person's refusal of … consent should always over-rule [that of] the parent's or guardian's consent'. Finally on this point, in the UK, the Mental Capacity Act of 2005 (HMG 2005) requires people who are in a support role to assume those in their care have the capacity to make autonomous choices unless non-capacity can be proven. It is worth noting, however, that this act does not apply to people under 16, within the age band of our participant recruitment.

Anonymity, confidentiality and participant recruitment

Anonymity and confidentiality are two related concepts. Anonymity is achieved when all information relating to the identity of the participant is removed or absent. As Farrimond (2013) points out, this may allow participants to speak freely, to prevent any potential harm in being identified and to conform to data protection requirements. Confidentiality is where the researcher knows the identity of the participant, but does not divulge this to any third party—as is common in research to have identifying information (such as a full name, contact details) (Allen 2017). Indeed, it is rare not to, as people have to sign consent forms, etc., although it is possible to do this via gatekeepers or other intermediaries. However, names are generally anonymised, although participants may choose to waive this right, because they feel more a sense of participation and inclusion (Farrimond ibid).

The consent forms included confirmation that the information sheet had been provided, read and understood, and that the opportunity had been available to ask questions. The adult (post 18) participants in our study had the choice of:

- Their contributions being anonymised, although recognising that as many care leavers felt their voices had not been heard whilst they were in the care system (or in their records), they may wish to use their own identities in any dissemination of the project findings. However, we considered the younger participants to be more vulnerable and elected to not offer this choice of being named. This may seem controversial, but with this cohort there are security and privacy considerations.

- Leaving the research at any time, without giving a reason and having any contributions expunged from the record (the information sheet also made it clear that those who declined to participate would be welcome to change their minds and do so after all!). As was made clear in the participant information sheets, it is always, of course, impossible to completely expunge published material. Even article retraction is far from ideal, as copies will have been made, downloaded, shared, etc.

In our case participants involved in both phases of the project were shown the final drafts of articles intended for submission for publication, with those quoted or paraphrased (anonymously) shown their contributions and given the opportunity to have these removed. This policy raises ethical issues around the longer-term power of participants, in that once published, co-researchers (and indeed, academic researchers) are powerless to change anything. However, no work would ever be released to the public if authors and other contributors did not accept this.

As we completed an earlier phase of MIRRA with a group of 'co-researcher' care leavers who were keen to continue their involvement, we were only required to recruit young people to participate in the user testing phase. To this end, we contacted Local Authorities and other appropriate organisations. Individuals (potential 'gatekeepers') from these who were able to help, however, informed us, in different ways, that they were unable ethically to approach the young people directly, but were required to communicate with the legal guardian in the first instance, to either seek permission to talk to their young person or ask the guardian to do so, depending on circumstances. Although this was frustrating, we accepted it, as we also felt that it was not good ethical practice for minors to be invited to participate without the knowledge of their legal guardians. However, our information sheet for guardians asked that the person in their care be given autonomy ('We would be grateful if you could read through it together, to see if it is a project and an activity which your child would like to undertake. We would really like the decision to be your child's, even if that is against your personal preference. However, we understand if you have a strong reason to say no, and you both have to agree'.) Also, we were also keen not to try to persuade gatekeepers—on whom we depended so much—to do anything with which they were not comfortable. Thus, we were required to produce information sheets and consent forms for the youth participant, the guardian and the gatekeeper (and for the knowledge exchange phase, for care leavers and social workers).

The project, already working on the short timescale of one year, was further condensed by Covid-related staff absence and a protracted Ethics Committee submission. This meant the elaborate recruitment process had to be completed within a very short time frame. This was made more acute by the vulnerable nature of the cohort, which made it imperative to take as much time as possible to build up a sense of trust, understanding and mutual respect. Ordinarily this would entail several visits to a potential fieldwork location in person and talking to a gatekeeper, before then meeting with potential participants, to explain the project and answer questions, before undertaking any formal research. Both the time constraints and Covid travel/contact restrictions made this preparation impossible. This and other considerations (such as organisational 'chain of command' delays; competing demands and

availability) conspired against recruitment, and we were only able to work with one person under the age of 18.

It is important to note that our research proposal was completed (and funding agreed) before the pandemic. In the light of the difficulties it occasioned, and possibly our own naivety about how long recruitment would take, it was perhaps unfeasible to attempt the project within the requested time period. Also, at the time of our tests with the sole participant, we were not aware that this person would not be joined by others later. Thus they were not burdened with the knowledge of being the sole representative of their generation.

Despite these barriers, there were several reasons why we chose to continue the research as planned. These were:

- The app specification was more of a 'proof of concept' to be further explored later, and so we did not feel the research lacked credibility in spite of having a sole participant. We regard the work as ongoing and are exploring further funding opportunities;
- We could have reverted to user testing with our care leaver cohort. However, we felt that the contribution even of only one 13–17 year old gave the app testing a legitimacy that would have been lacking by using only older people no longer in the system;
- We were also in debt to all the gatekeepers (and the gatekeeper finders!) who worked so hard on our behalf—and who were subsequently very apologetic that they were unable to recruit more participants.

On a more positive note, we were immensely pleased that all of the care leavers from the first phase of the project elected to continue, despite the fact that its focus had changed and that consequently, their contributions would be qualitatively different. Perhaps not surprisingly, they were keen to have a voice in how recordkeeping could be improved (and, crucially, made more participatory). A reviewer of the first draft of this paper commented that this was testament to the research team's ability to establish trust and to the success of phase one with regard to participants' perception of value of the research and benefit/value of their own involvement.

Finally, in researching with vulnerable participants, there is a case for reviewing consent through time. Watchman (2016), for example, working with people with Down Syndrome and dementia, sought consent every time a participant had contact with a researcher. The short timescale for MIRRA+ and, for the youth participants at least, brevity of contact both led to the decision not to add yet another layer to the process. In any case, it is simply good etiquette, when arranging to meet someone for a second time to politely ask their permission, regardless of any prior commitment.

Risk and benefits

Even in non-medical research, there are a number of ways in which an individual may be put at risk. More positively, there are many ways in which participants, their cohort and wider society can benefit from research.

Risks include those related to the emotional state of the participants, reputational risk or even legal issues arising. The first may include distress caused by discussing personal issues, the second by participants revealing a behaviour or belief that may cause reputational damage—to a colleague or an institution or to themselves, and the third by confessions of drug mis-use or other illegal behaviour.

Although the current stage of our study is not about personal experiences, individual participants may nevertheless disclose information about themselves or others whilst discussing their experiences of accessing records. Some of this information may be difficult or upsetting to recall. For phase one, we provided details of organisations which offer appropriate support. In addition, support organisations including CLA are represented on our Advisory Group and are able to offer support to individuals.

For their part, professionals involved in phase one ran a slight risk of disclosing information or opinions that could have been harmful to their professional status or career progression. This risk did not materialise, but in any case would have been mitigated through the confidentiality procedures in place. There was an extremely low risk that they would make disclosures about a past criminal offence they have knowledge of or committed (e.g. the suppression of documentation relating to child abuse). Again, this did not occur, but the protocol was for the researcher to report it to the principal investigator to determine whether the public good of reporting this to the authorities was greater than the participants' right to confidentiality. This was made clear in the consent form.

Another risk is that the care leaver co-researchers might have felt themselves to have less of a voice than the academic researchers or the professional workers. As university researchers we knew we were entering into a partnership with adult care leavers in a position of structural power. In addition, care leavers were under the control of social workers as children and young people and continue to be beholden to such practitioners when seeking access to their records. Social care researchers may have knowledge about and 'expertise' on care leavers as a group that can obscure their unique personal experiences. Recordkeepers, who redact care records according to the requirements of the Data Protection Act, may know more about a person's childhood than a person knows themselves. We resolved to continue fostering an atmosphere in which all participants were able to speak and express their own views and experiences. The decision to approach research from the perspective of care leavers themselves, prioritising their needs and experiences, was vital to rebalancing power relationships. The service provider groups were made aware of, and accepted, this before fieldwork began. Also, an Advisory Group was created which comprised of representatives of all participant groups—particularly from organisations that advocate for adult care leavers—giving a voice to the latter's experiences at all levels of the project.

Finally on risks, a word needs to be said about younger participants. As noted above, we were acutely aware of a power relationship/imbalance between the gatekeepers and the prospective participants. With regard to this younger cohort, we were cognisant that young people in care may have felt pressurised to take part in the research if directly approached by their case or social worker (for example). We have worked with vulnerable groups in the past (e.g. Williams 2017; Sexton and Sen

2018) and understood the need to impress on our gatekeepers the voluntary nature of participation, autonomy of choice and absence of any negative consequence or inference regarding those who choose to decline our invitation. At the beginning of the user testing session, care was taken to put the participant at ease, and also to emphasise (as did the consent form) that withdrawal was always an option, with no negative consequences or implications.

The vulnerable nature of the cohort was demonstrated by young people who had been recruited to participate then electing (or having) to withdraw. For example: 'One of our young people who wanted to get involved has had to go away to a holiday lodge this week … due to having some difficult news and needing to process that, and another … is on a bit of a downward curve just now and struggling to engage with anything. They were both really positive 2 [sic] weeks ago'. In another case, a young recruit simply changed their mind. Finally, there was an example where a gatekeeper had thought of a suitable participant and was 'hopeful' of recruitment but, before taking any steps, discovered that 'she had just received some upsetting news so didn't want to push it with her'.

Of course, it is hoped that any research project will only result in benefits. Those to the participants themselves may include an increase in knowledge about a subject (or about the process of researching a subject), an increase in self-esteem, perhaps occasioned by their achievement in contributing to a piece of research or (maybe more important to them) the altruistic benefit of helping to improve the situation for themselves or their community. Sieber and Tolich (2013, p. 28) describe this as feeling worthwhile, and also add 'kinship benefits', described as 'the feeling of closeness to persons or the reduction of alienation'. At a community level, benefits may include empowerment or self-advocacy, policy changes or other political benefits, or greater community cohesion.

With regard to MIRRA+, we found that, as with our earlier study, a number of participants were motivated to take part through a desire to effect change to information rights protocols. We are hoping that these people will benefit from the opportunity this work gave to contributing to a process which is personally meaningful to themselves and their sense of wellbeing.

Conclusion

This paper has discussed the topic of research ethics in the context of a programme of research (MIRRA/MIRRA+) that developed a 'participatory recordkeeping system specification' to give young people in care a voice in their own care record, in which the fieldwork involved the young people themselves and care-experienced adults. A consideration of the ethical issues that such a study entails highlights the numerous and diverse factors that have to be taken into account. These include the broad nature or paradigm of the research, why it is being carried out and for whom; and particular considerations such as 'labelling', both generally ('participants' or 'co-researchers') and that of appropriate terminology for someone who

has spent time in 'care'.[4] The paper has shown that ethical issues around recruitment may require much planning and thoughtful preparation. The involvement of a 'child' cohort—with the added characteristic as also being 'in care'—added an extra layer to protocols around participation. This included juggling the contrasting requirements of offering autonomy of choice whilst ensuring the protection required—a balancing act one of the present authors has also needed to undertake in work with people with learning disabilities (Williams 2020, 2021). Ethical issues around informed consent, recruitment and participation of this cohort were particularly complex and required much additional bureaucracy, patience and flexibility. The research team did not quite overcome these barriers to the extent that we would have liked, so in one sense the project could be considered to not have been 100% successful. However, despite the extensive preparation required and multiple factors to be considered, the rewards for undertaking research that truly involves and benefits participants surely make the efforts of both the academic researchers, and also participants and the support network through whom recruitment takes place, both worthwhile and immensely satisfying.

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[4] Of course, ethics of data labels or metadata schema for the recordkeeping app itself are outside the scope of this paper, although (presumably) this remains a key data ethics issue and research question (to be informed by care leaver views) for the broader project/next stage of the research and prototyping a recordkeeping app.

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