

NOVELLA



NARRATIVES OF VARIED EVERYDAY  
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# NOVELLA Working Paper: Narrative Research in Action

**The ethics of secondary data analysis: Learning from the experience of sharing qualitative data from young people and their families in an international study of childhood poverty**

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# The ethics of secondary data analysis: Learning from the experience of sharing qualitative data from young people and their families in an international study of childhood poverty

## Abstract

This working paper focuses on secondary analysis, an aspect of research practice that is sometimes assumed to pose few ethical challenges. It draws in particular on the experience of a collaborative research project involving secondary analysis of qualitative data collected as part of an ongoing international longitudinal study, Young Lives ([www.younglives.org.uk](http://www.younglives.org.uk)), and sets this alongside a wider review of regulatory guidance on research ethics and academic debates. Secondary analysis can take many forms, and bring many benefits. But it is more ethically complex than regulatory frameworks may imply. Whether or not data are *publicly* archived, ethical considerations have to be addressed, including responsibilities to participants and the original researchers, and the need to achieve a contextual understanding of the data by identifying and countering risks of misinterpretation. The considerations raised here are intended to aid ethical research practice by supporting planning and reflection – for primary researchers who are planning to archive their data, as well as for researchers embarking on a qualitative secondary analysis. Not least, our experience highlights the importance of developing and maintaining trusting relationships between primary and secondary researchers.

## Introduction

Discussions of research ethics can sometimes ‘over-emphasise the technicalities of data gathering, focusing on procedures for ensuring informed consent and information provision in particular, at the expense of attention to other stages of the research process’ (Wiles and Boddy 2014, p5). In this working paper, we focus on an aspect of research practice that is sometimes assumed to have few ethical challenges: secondary analysis. We draw in particular on our experience within a collaborative research project involving secondary analysis of qualitative data collected as part of Young Lives, an ongoing international longitudinal cohort study. As authors, we represent different perspectives in that collaboration: Virginia Morrow is part of the research team at Oxford University that coordinates the Young Lives study; Janet Boddy and Rowena Lamb are part of an ESRC National Centre for Research Methods Node, NOVELLA (*Narratives of Varied Everyday Lives and Linked Approaches*), which is applying narrative methods to the analysis of data from a range of secondary sources across several projects. One project, the Family Lives and the Environment study, has re-analysed Young Lives qualitative interviews with eight families in Andhra Pradesh in India (Shukla et al., 2014).

Here, we reflect on our experience of sharing and re-analysing these interviews. We situate our reflections within a wider review of relevant literature, regulatory guidance and academic debates. By sharing our experiences – including some of the ethics tensions we have faced – we aim to support other researchers in planning and conducting the secondary analysis of qualitative data, helping them to recognise – and so address – ethics considerations in their own work. Secondary analysis can take many forms, and bring many benefits. But our experience suggests it is more ethically complex than regulatory frameworks may imply: particular ethics considerations arise when we (re)turn to existing data.

## Data archiving and data sharing: a regulated ethical practice?

### *The regulation of data sharing*

The Oxford English Dictionary dates the etymology of ‘archive’ (as a noun) to ancient Greece, referencing John Dryden’s 17<sup>th</sup> century translation of Plutarch’s lives. Only recently, however, has archiving been related to primary empirical research data, and allied to data access. Previously, researchers have often been expected to destroy data after the end of a research project, and this has been justified in relation to confidentiality, data protection and informed consent (Mauthner 2012). Writing in 1998, Thorne (p547) observed that ‘there are increasingly restrictive limits to the number of primary databases that funders will be inclined to support’. This has changed, for economic reasons, as well as because of arguments about the benefits of data sharing.

Research funders now commonly require data to be archived. The ESRC Research Data and Open Access Policies set out this expectation. The ESRC Open Access Policy states:

More specifically, we require research data arising from ESRC-funded research to be made available to the scientific community in a timely and responsible manner. ESRC grant holders are expected to make use of existing standards for data management and to make data available for further re-use.

(ESRC 2010, p3)

Guidance on good conduct in research has contributed to a shift in expectations over recent years, from an assumption that it is ethical to ensure data are destroyed after the end of a study, to an apparent expectation – embedded in ESRC policy since 1995 – that data will be preserved in an archive *and* made publicly available to other researchers via archiving and sharing. The default position is that data should be shared, and the justifications given can be seen to draw on a rhetoric of moral ethics. For example, the ESRC Data Policy states that:

Publicly-funded research data are a *public good*, produced in the *public interest*.

(ESRC 2010, p2; our emphasis)

Research Councils UK (RCUK), the umbrella body within which ESRC sits, published its Open Access policy in 2013. This requires a statement from each study funded by a research council explaining how underlying research materials, including data, can be accessed (although it does not mandate that the data must be made open). RCUK policy acknowledges that there may be exceptions to this

default position, if 'there are considered to be good or compelling reasons to protect access to the data' (RCUK 2013, pp4-5; see also ESRC 2010). A default expectation of secondary data use also applies to *new* data collection: ESRC grant applicants have to justify collecting new data, by explaining which existing datasets have been reviewed, and why they are inadequate for the proposed research.

The ESRC policy makes reference to *Principles and Guidelines for Access to Research Data from Public Funding* published by the Organisation for Economic Co-operation and Development (OECD 2007). These principles were developed to enable 'cost-effective access to digital research data from public funding', noting that 'access to research data increases the returns from public investment' (2007, p3). Over time, this economic imperative has become allied with a moral imperative.

### ***Potential benefits and risks of data sharing***

There are many good reasons for data archiving and data sharing, as noted by researchers such as Van den Eynden et al (2011) and Bishop (2013). Here we review these arguments – and in doing so we also highlight concerns about the potential ethics risks in sharing data. We do this from our position as researchers actively involved with 'secondary analysis' projects – fully cognisant of the manifold potential benefits of data sharing and re-analysis. But the ethics questions raised by secondary analysis of any form of data are many and various. To date, the bulk of attention has focussed on the ethics of *archiving* qualitative data – for example, focusing on appropriate consent processes (e.g., Van den Eynden et al. 2011). Much less has been written about the ethics of *re-using* data.

The UK Data Archive (Van den Eynden et al. 2011, p3) sets out a substantial list of arguments in favour of data sharing, which include a mix of scientific, pragmatic or utilitarian, and moral arguments (Mauthner 2012). Utilitarian arguments for data archiving and data sharing are centred on two related factors. First is cost. Primary data collection is expensive; re-use of data maximises the efficiency of the primary funding investment and is cheaper than funding more new data collection (though there are costs involved in preparing data for archiving, and the process can be very expensive). Second, and relatedly, developing digital technology means that archiving and data sharing is, at first sight, relatively simple and cheap. Van den Eynden et al. (2011, p3) in guidance for researchers about archiving data highlight the 'ease with which digital data can be stored, disseminated and made easily accessible online to users'.

However, the proliferation of digital forms of data and the accessibility of data through the internet bring new ethical challenges, for example, related to informed consent, confidentiality and anonymity, data protection, use of secondary data beyond the original purpose of the research, and indeed what 'counts' in terms of data ownership or consent in the context of digital social media. Carusi and Jirotko (2009, p288) cautioned that guidelines, policy and practice lag behind the reality of new technologies, which 'are pushing us beyond existing practice and ... often challenging its moral grounds'. Further recent developments in data protection, freedom of information and privacy legislation add to these debates, by highlighting the potential vulnerability of institutions *and* individual researchers. Charlesworth (2012) draws attention to the 'grey areas and overlaps between ethical considerations and legal requirements', citing examples of data being requested through

Freedom of Information Requests, and highlighting increasing concern about the potential liability of both researchers and their institutions for legal breaches. One might ask, what is a researcher to do?

The use of archived data for researcher training is a further potential benefit highlighted by Van den Eynden et al. (2011). When the primary beneficiary of a study is a student, gaining knowledge and a formal qualification, is it justifiable to conduct ethically sensitive research with potentially vulnerable individuals? Or is it better for the student to learn from re-analysis of existing data? Archived data are not only beneficial for student and early career researchers, but can provide a valuable resource for researchers in future years, giving historical insight into the development of a discipline or field of study (see for example, Gillies and Edwards 2011).

*Moral* arguments centre on the ‘public good’, making the fullest possible use of research, ensuring better use of public money, and – especially in researching sensitive topics – ensuring that potentially vulnerable populations are not over-researched. Re-use aims to reduce the risk of burden on respondents, and the potential imbalance between risk of harm and benefit in research (Mauthner and Parry, 2009, 2013). Data access is framed as part of a drive for openness and transparency, but those entitled to open access extend far beyond the research community, and specifically includes those who may wish to (re)use research data for commercial purposes.

Mauthner (2012) questions the *a priori* assumption that there should be common ownership of research data generated through publicly funded research. She argues that this assumption is both morally questionable, and potentially ethically risky if potential secondary uses are discordant with the original research objectives. She cites Christie’s (2011) report of an attempt by the tobacco company Philip Morris International to use Freedom of Information legislation to access research data on young people’s attitudes towards smoking. Gerard Hastings, who conducted the original research (with funding from cancer charities), described the request as ‘morally repugnant’ (Christie 2011, p d5655). In an example such as this, what place remains for the researcher’s moral concerns about the potential (re)use of their research?

This is not an objection to data sharing *per se*, but a concern that the ethical complexity of secondary analysis can be obscured by funder requirements for data sharing. This specific aspect of research ethics has effectively become regulated by default, as a judgement by the *funder* and not the ethics committee: data should be shared unless (exceptionally) the funder judges that a waiver can be justified.

Researchers such as Carusi and De Grandis (2012) have criticised the elision of *ethical research practice* with *ethics regulation*, such that:

The process of ‘getting through ethics’ and getting the necessary stamp of approval from the relevant institutional section is ‘doing ethics’.

Carusi and De Grandis (2012, p125)

The identification of ‘doing ethics’ with ‘getting through ethics review’ creates a risk that ethics questions focus on data gathering, with the result that (re)use of data is either seen as ethically unproblematic or ignored. However, the ESRC Framework for Research Ethics (2010, p25) acknowledges that ‘the fact that an original piece of research has gone through ethics review for its

collection does not rule out ethics issues arising over its secondary use'. Our experience of working together on a project that has shared and (re)used data has illuminated these debates. In the following sections, we highlight the ethics questions encountered in the process of our secondary analysis, in order to:

- identify key ethics risks and challenges;
- reflect on the strategies we used to address those challenges; and
- consider wider lessons for other researchers.

## The studies

The collaboration on which this Working Paper is based brought together the Young Lives study and the National Centre for Research Methods NOVELLA Node, through the Family Lives and the Environment project.

### *Young Lives*

Young Lives<sup>1</sup> is an on-going four-country longitudinal study of children growing up in poverty. Starting in 2001-2 as a child-focused household survey<sup>2</sup>, a qualitative component was added in 2006; the study runs until 2017. To date, three rounds of qualitative data have been collected, and a fourth is being developed at the time of writing (see Crivello et al 2013). The qualitative longitudinal research is designed to complement and extend the quantitative cohort study, using a multi-method approach to examine how poverty interacts with other factors at individual, household, community and inter-generational levels to shape children's life trajectories over time. The Young Lives qualitative longitudinal research (QLR), according to the researchers, aims:

to capture both what we as researchers assume to be relevant and important (e.g. the move from one school to a different school, or death of a parent) and what our research participants view as important (e.g. a child describing as a 'turning point' the day when he was given his own small plot of land to cultivate on the family farm).

(Crivello, Morrow and Streuli 2013, p2)

Young Lives qualitative data are gathered by research partners in each of the four study countries (Ethiopia, India (Andhra Pradesh), Peru, Vietnam), and a close working relationship has developed over the years between teams in the study countries and in Oxford (where the study is coordinated). The qualitative research has been designed and developed as a collaborative, iterative process, with teams in frequent contact, and the Oxford team involved in piloting in all four countries. Data analysis is also shared, and papers are co-written and/or shared, as well as being lead- or sole-authored by study country research partners.

Through this collaborative process, Young Lives researchers gain a collective understanding; close joint working is crucial for the Oxford team to ensure that data are read knowing the context and

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<sup>1</sup> [www.younglives.org.uk](http://www.younglives.org.uk) Gina Crivello leads the qualitative research in Oxford, and Yisak Tafere (Ethiopia), Uma Vennam, (India), Patricia Ames, Natalia Streuli, Vanessa Rojas (Peru), Huong Vu (Vietnam) are the lead qualitative researchers for each of the four countries.

<sup>2</sup> Survey data are archived at UK Data Archive; <http://discover.ukdataservice.ac.uk/series/?sn=2000060>

fieldwork teams. Misunderstandings and misinterpretation could be distorting – and hence ethically problematic – without close collaborative support from the local research team. Inevitably, those who have conducted fieldwork will have a different Given these considerations, the need for contextualised analysis, the cost involved in fully anonymising qualitative data, and the potential risks of identification of participants within a small qualitative sample that links a variety of data sources, the Young Lives qualitative data are not publicly archived. They have been accessed by the NOVELLA team as part of a formal funded collaboration.

### NOVELLA

The NCRM NOVELLA Node (Narratives of Varied Everyday Lives and Linked Approaches)<sup>3</sup> comprises three core studies, and two additional collaborative projects, details of which are available on the NOVELLA website. A key common strand in all five projects is the re-use of data (of different sorts) in order to advance narrative analytic approaches. The boundaries between primary and secondary analysis are not always straightforward, and the NOVELLA studies reflect that variety, ranging from analysis of publicly available archival documentary material, including some collected by NOVELLA researchers in their own previous studies and online data in the public domain to re-analysis of non-archived data. The Family Lives and the Environment project (FLE) involves a common form of secondary analysis, that is, the re-use of data collected by another research team for a different study (Young Lives).

The FLE team studied Young Lives data from eight families living in Andhra Pradesh, India (out of 200 families in the qualitative sample across the four study countries, 48 of whom live in Andhra Pradesh). For the Family Lives and the Environment study, cases were purposively sampled to inform both methodological and substantive aims, to improve understanding of the negotiated complexity of families' lives in relationship with their environments, and illuminate meanings of 'environment' in everyday family lives and family practices. They were not intended to be representative of Young Lives families, either in India or more generally. Beyond substantive concerns, a key methodological objective was to examine what (or whether) a narrative approach can contribute in secondary analysis of Young Lives data (see Shukla et al. 2014; Boddy 2014). The secondary analysis also aimed to inform methodological development for the second phase of the FLE study – new fieldwork in Andhra Pradesh and the UK, also conducted in collaboration with Young Lives researchers.

For each family case, six transcripts were analysed in depth – interviews with caregivers and children over three rounds of data collection. Reflecting the narrative methodological focus of NOVELLA, the secondary analysis conducted by Family Lives and the Environment researchers entailed a very close reading of each case. Such work is akin to the close-up of a macro-zoom camera lens, in comparison to the wide-angle reading of a cross-case analysis. The particular risk for a decontextualised *secondary* analysis is that one may see the wood in great detail, but fail to see the forest.

## Distance in secondary data analysis

Janet Heaton (1998, 2004) warned of the complexity of defining 'secondary data analysis'. Writing in 1998, she defined the term as encompassing the use of existing data, collected for the purposes of a prior study, in order to pursue a research interest which is distinct from that of the original work; this may be a new research question or an alternative perspective on the original question. Such

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<sup>3</sup> ESRC number: RES-576-25-0053; [www.novella.ac.uk](http://www.novella.ac.uk)

distinctions are less straightforward in practice, as the above overview of NOVELLA and Young Lives demonstrates. Within Young Lives, the Oxford team are not undertaking primary data collection themselves, but rather working in a coordinating and collaborative role with the lead qualitative researchers in each country. All the NOVELLA studies involve returning to previously collected or recorded information, but the studies vary in the extent to which different researchers might be construed as conducting 'secondary data analysis', since some have also been involved as primary researchers.

There is a *spectrum* of secondary analysis (Heaton 1998, 2004; Coltart et al. 2013), with variation in the extent to which the (re)analysis is 'secondary', and relatedly, the extent of researchers' distance from the original information. Coltart et al. (2013 no page numbers) argue that the conceptualisation of a spectrum – recognising the varied forms of primary and secondary data – is useful in 'overcoming unhelpful "us" and "them" characterisations of primary and secondary analysis'. Distance can take different forms. Secondary analysis in Family Lives and the Environment spans geographic, cultural, linguistic, and temporal distance.

There are important ethics risks in research that seeks to cross cultures, not least because of the potential to distort or misrepresent data analysed at a distance, given insufficient local knowledge and contextual understanding (Fossheim, 2013). Risks of misinterpretation arising from lack of contextual knowledge are likely to be exacerbated by the secondary analyst's distance from the original data, inherent in a secondary analysis (e.g., Parry and Mauthner, 2004, Mauthner, 2012, Carusi and Jirotko 2009).

Of course, all analysis is a matter of interpretation, as Josselson (2004, p3) writes:

Because meanings cannot be grasped directly and all meanings are essentially indeterminate in any unshakeable way, interpretation becomes necessary, and this is the work of the hermeneutic enterprise.

However, the interpretive stance of the analyst will be influenced by their relative distance from the interview interaction – and this can create tension between primary and secondary researchers. Josselson (2004) distinguishes between two forms of hermeneutics, or interpretation (after Ricoeur, 1970, 1981, cited in Josselson op cit). On the one hand is a focus on *restoration* of meaning, which Josselson describes as 'characterized by a willingness to listen, to absorb as much as possible the message in its given form'. This resonates with Kingori's (2013) account of biomedical research in Kenya, which highlights the empathy that fieldworkers feel for participants. On the other hand, hermeneutics may be approached as a *demystification* of meaning, as the researcher seeks to interpret meanings that may be hidden or not transparent. This hermeneutic distinction is relevant to secondary analysis: without the contextual understanding that arises from having been part of the interview interaction, the analyst is perhaps inevitably engaged with demystification as well as restoration of meaning.

A further difference between Family Lives and the Environment (FLE) and Young Lives studies derives from the FLE study's objective of applying a narrative analytic frame to secondary analysis of interviews that were not collected for the purposes of narrative analysis, but were intended for thematic analysis. There are obvious limits on the contextual understanding that frames a secondary analysis as the analyst



inevitably operates at a distance from the research context. Young Lives is primarily a study of childhood poverty and data are gathered with the explicit intention of undertaking policy-relevant analysis and conceptual work. It is not and was never intended to be a methodological or narrative study, though the methodological learning from Young Lives is a resource documented for other researchers, for example in technical notes and guidance<sup>4</sup>. Langellier (1999, p128) commented that “approaching personal narrative as performance requires theory which takes context as seriously as it does text.”

The relationship with the data is also temporally complex. The qualitative component of Young Lives began in 2007, but original research is still ongoing, with active relationships between the Oxford team, participants *and* local Young Lives fieldwork teams. The FLE analysis has also been conducted at a geographic and cultural distance from the original research – by UK researchers based in London. This has again shifted over the course of the project, as the FLE team moved into the second phase of work and conducted piloting and new fieldwork in Andhra Pradesh, working in close collaboration with the qualitative team in India (but still as ‘outsiders’ to Andhra Pradesh) and not in the same areas as the original fieldwork.

Interviews for Young Lives are conducted in local languages – usually Telugu or Urdu in Andhra Pradesh – and recorded, transcribed and translated. This creates a linguistic distance from the interview conversation which has particular ramifications for narrative approaches that attend to the linguistic devices used in story-telling (e.g., Bauman 1986; Riessman 2003). Close reading and line by line analysis – attending to choice of words, or examining repetitions, for example – may not be warranted when interviews are read in translation, and were not transcribed with narrative analytic reading in mind.

Interviews and analysts crossed countries as well as languages, and this has particular implications for narrative analysis in several respects. First, there are questions about understanding the cultural and contextual nature of genre story forms – given the difference between the analysts’ cultural formation and that of the local Young Lives qualitative team in Andhra Pradesh.

The multiple forms of distance from the primary data inherent in the Family Lives and the Environment study present a kind of ‘double jeopardy’ of ethics risk, of both mis-interpretation and mis-representation of the research data. FLE analysis differed in both research objectives and analytic approach from the Young Lives study, where qualitative analysis – whether case-based or cross-case has predominantly followed a thematic approach. So, we began our collaboration with an apparent disjuncture, in both research objectives and analytic approach to the data. Our priorities were not the same. At the same time, we began in a spirit of shared enquiry, and with a shared interest in ethical research practice<sup>5</sup>.

In understanding and addressing the potential ethics challenges of the work, the methodological focus of the FLE study – as befits its positioning within the National Centre for Research Methods –

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<sup>4</sup> <http://www.younglives.org.uk/what-we-do/longitudinal-qualitative-research>

<sup>5</sup> Each author has longstanding interests. Our interest in research ethics dates back to Lamb’s work within the King’s College London research ethics and governance systems, Morrow and Boddy’s previous collaboration on the ESRC funded *Ethics Guidebook* website ([www.ethicsguidebook.ac.uk](http://www.ethicsguidebook.ac.uk)), Morrow’s interest in ethics of research with children, dating back to the mid-1990s (Morrow and Richards 1996, Alderson & Morrow 2004, 2011), and Boddy’s work on research ethics and governance in England (e.g., Boddy et al. 2006; Boddy and Oliver 2010).

has been of key importance. Over the first year of the project, we worked together to address the practical and ethics considerations that have arisen from the Family Lives and the Environment study's re-use of Young Lives data. Through the remainder of this exploratory paper we draw on that learning, aiming to contribute to ongoing discussions about data archiving and secondary data use. By highlighting the particular ethics considerations encountered in secondary data analysis, we do not seek to negate its value. Rather, we aim to respond to Coltart and colleagues' (2013, no page numbers) challenge for researchers to engage 'around a professional and ethical agenda which emphasises the multiple productive pathways for reworking qualitative data and building knowledge across the primary/secondary spectrum'.

## Overcoming ethical challenges in secondary analysis

One of the key tenets of research ethics, dating back to Socratic conceptions of virtue – and over the last century, to international ethics codes such as Nuremberg (1947) and Helsinki (1964) – is that research should avoid harm. In relation to secondary use, this is the harm of stigma or prejudice, as well as misrepresentation. In the sections that follow, we explore questions related to informed consent, co-construction of data/researcher positioning, guidelines on anonymisation of data, and researchers' reputations, and finally we make some suggestions that we hope will be helpful to other researchers who consider sharing data.

Coltart et al. (2013) synthesise a long-running debate in the social sciences about the questions raised by the archiving and secondary analysis of qualitative data. They note that a drive to encourage archiving and secondary use means that 'concerns about the professional and ethical challenges posed by QSA [Qualitative Secondary Analysis] have sometimes been pushed towards the background in secondary analysis work, or viewed as less vexing than previously thought' (op. cit., no page numbers). Mauthner and colleagues (e.g., Doucet and Mauthner 2012) have made a critical contribution to identifying the challenges of re-using qualitative data, whilst others (e.g., Bishop, 2009, 2012, 2013; Corti, 2012, Moore 2006) have sought to move debate – and practice – forwards by highlighting methodological, conceptual and practical developments. Mottier (2005, no page numbers) comments that 'if we overemphasise the interactionist and contextual nature of data collection, secondary analysis of qualitative data would ... seem pointless'. Such arguments are consistent with the objectives of the NOVELLA studies, which are built on an assumption that there is value in qualitative secondary analysis. However, as Irwin et al (2012, p67) point out, whilst 'quantitative research is predicated on standardisation ... qualitative research is centered on specificity, context and the embedded nature of meaning. By its nature then, it engenders particular difficulties for secondary users.'

The question of distance was a particular concern for the Family Lives and the Environment study because of its focus on narrative. A key feature of narration is its communicative nature: stories are told to 'communicate meaning to listeners' (Reissman 2003, p334). Bruner (1991) emphasises intentionality as a key feature of narrative interpretation, considering *why* the story is told *how* and *when* it is, and interpreted as it is. This framing could imply that narrative analysis depends on closeness to the original data, on understanding of the communicative context through knowledge of the speaker *and* listener in an interview. Irwin et al (2012, p67) do not write about narrative analysis, but their advice is relevant:

‘while primary analysts have a privileged relationship to the data they have generated, ‘being there’ is not the final arbiter of the adequacy of understandings, although a sufficient understanding of proximate contexts is a crucial component of analysis’.

Sufficient understanding of proximate contexts is necessary to mitigate the risks of misinterpretation and misrepresentation associated with secondary data analysis. This also entails awareness of the *limits* of understanding, taking care to recognise what cannot be known and should not be assumed by the secondary researcher. At the same time, this awareness of the limits on contextual understanding can be seen as an *ethical* imperative for both primary and secondary researchers, in relation to their responsibilities for ethical practice in data use and re-use since, even in primary research, there are many things that remain unknown.

Our work began with close reading of Young Lives publicly available resources on methodology<sup>6</sup>, alongside discussion with the Young Lives researchers in the UK and in India. After reading about the Young Lives objectives and methodology, the FLE team developed their understanding by reading data gathering reports which contextualise the interview data, and only at this stage did they begin reading transcripts. Throughout, FLE researchers relied on questioning and discussion between FLE and Young Lives researchers. This work was further supplemented with contextual reading of group discussions with children, and interviews with community leaders. This extensive process of contextualisation was embedded in the research design, supported through funding for Young Lives researchers’ time on NOVELLA and formal data access agreements. This work formed a critical underpinning for secondary analysis of the family cases and was methodologically crucial, to ensure adequate contextual understanding, but it was also *ethically* necessary, to avoid misreading data at a distance.

## Fully informed consent?

Consent can be seen as the central pillar of ethical research, based on the Nuremberg Code principle that research participation should be voluntary, but the notion of *fully informed* consent raises particular considerations for data archiving and re-use. When data are to be archived and re-used, the participant and the researcher cannot know what the data will be used for in the future (Alderson 1998, Hadfield, 2010, Mauthner 2012, Williams et al. no date). The biobanking literature has used the notion of ‘broad consent’ to encompass potential (unknown) future uses, but as Whitley et al (2012, p233) observe, this ‘pragmatic solution [...] arguably fails to meet the tenets of informed consent as provided by the 1964 Helsinki Declaration’. In seeking participants’ consent for data sharing, we are effectively asking for consent to uncertainty; if future uses are unknown, consent cannot be claimed as fully informed. Guidance on the UK Data Archive (2011) website suggests that this is not problematic; researchers should treat participants ‘as intelligent beings, able to make their own decisions on how the information they provide can be used, shared and made public (through informed consent)’<sup>7</sup>.

But is it reasonable to ask for consent to uncertainty? Moreover, are the aims and purposes of research *ever* fully understood? Corrigan (2003, p770) warns against seeing consent as a panacea,

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<sup>6</sup> [www.younglives.org.uk/what-wedo/research-methods/methods-guide](http://www.younglives.org.uk/what-wedo/research-methods/methods-guide)

<sup>7</sup> <http://www.data-archive.ac.uk/create-manage/consent-ethics/legal?index=0>

which overemphasises individual autonomy, and ‘not only reduces the significance of other ethical principles but ignores the cultural context within which the process of consent takes place’. At the same time, the UK Data Archive’s guidance makes reference to ‘active debates about whether consent is always necessary or even if it is epistemologically possible’<sup>8</sup>. In that context, it is equally relevant to ask *why* people consent to participate in research at all (whether or not they are deemed potentially vulnerable because they are children, or live in difficult circumstances). Research spanning social and medical sciences indicates that *trust* is key (e.g., Corrigan 2003; Crow et al. 2006): the participant’s trust in the researcher or other worker who is tasked with seeking consent, *and* their trust in the value of (the) research.

The centrality of trust in the process of consent has particular implications for consent to archiving and re-use. If potential future uses cannot be known, what does this mean for trust between research participants and researchers? What responsibilities do primary *and* secondary researchers have towards participants? Mauthner (2012, p14) has written of the obligation she felt to explain archiving, as part of the consent process, the risks involved and ‘potentially morally harmful effects’ for her interviewee ‘of seeing his story interpreted through different lenses or used for different purposes’.

It has been argued that respondents are very unlikely to see the stories told about them, to read what researchers write about them in obscure academic journals (Thompson 2004). But this may be a dangerous assumption, particularly in the new, open, digital age, with open access outputs and findings highlighted through visual and other media, including social media (see Clarke 2013; Snee 2013). Moreover, participants are not merely passive generators of research data, but may actively seek out information about studies they have been involved with. Young Lives in Peru has its own website, Niños del Milenio, which has photos of (non-Young Lives) children posted on it for communications purposes. One mother of a Young Lives child in a remote community raised concerns about this in the consent process at the second round of qualitative research, when she reported that the older sister of the child had accessed the website, and interpreted it as an adoption agency (Morrow 2009). Participants can of course also access secondary use publications – a participant who searches online for “Young Lives” could also find NOVELLA publications (including this paper).

## Co-construction and reputations

Qualitative secondary analysis can act to scrutinise other researchers’ practice – and so potentially to compromise researchers’ reputations (see Gillies & Edwards 2011, 2012; Bishop 2013). Caplan (2008) describes attempting to archive some of her fieldwork records and the uneasy sense that archiving is exposing of her research practice. Gillies and Edwards (2011, 2012) also commented on the uncomfortable questions raised about ‘good’ research practice, in reading Dennis Marsden’s fieldnotes and research data posthumously. They highlighted the centrality of context – both in relation to the understandings they gained from discussions with Marsden’s widow, Jean, who was closely involved in the work – but also in recognising the historical context in which the work was carried out.

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<sup>8</sup> <http://www.data-archive.ac.uk/create-manage/consent-ethics/consent>

In an interview-based study such as Young Lives, the secondary analyst works with the interview transcript, and the interviewer's practice is visible alongside (and intertwined with) the participant's account. For a narrative analysis such as that conducted in the Family Lives and the Environment study, 'narratives are keyed both to the events in which they are told and to the events that they recount' (Bauman 1986, p2). In a qualitative secondary analysis of this kind, the co-construction of data between researcher and participant is often an explicit focus of the work, and this raises distinct ethics considerations.

To take one example from the Family Lives and the Environment study, the narrative approach employed in data analysis means that we are interested in the interview as a site for identity performance, through the construction of narratives of everyday life (see for example Boddy 2014). In this context, it is relevant to consider the way in which participants construct themselves – their positioning and identity – relative to the interviewer (Phoenix 2013). In this context, even the cornerstone of ethical practice – the explanation to secure informed consent – inevitably functions (and can be analysed) as a form of positioning between researcher and participant:

Before starting, I will introduce the purpose of my research and myself. My name is [X]. I have come from [place], and it is famous as a pilgrim centre and [...] there is a university in which I work. We are here on a research project. This study is called Young Lives. It is regarding children's lives. This research is done in Andhra Pradesh, India, Vietnam, Peru and Ethiopia.

This explanation – part of the consent process – is audio-recorded and transcribed in order to comply with the requirements of research ethics approval for the Young Lives study<sup>9</sup>. The process inevitably requires researchers to position themselves 'as researchers' to explain what the research is about, where they are from, who is funding the study and why. All of this necessarily makes salient the difference between the researcher and the 'researched'. To do otherwise would be disingenuous at the very least. But in the context of a narrative analytic framework, this opening sets a context in which to understand the co-construction of the narrative that follows. Within this analytic framing, the opening words introduce the interviewer to the participant, and so form a key element in understanding the narratives that the participant constructs *for that interviewer, in that context*. This focus on co-construction raises another ethical issue, namely that fieldworkers in Young Lives may not expect their words to be subjected to this kind of analytic scrutiny. What is the expectation of *interviewers* in relation to secondary analysis? Should they be expected to agree to potential secondary uses? Is external scrutiny of their words to be expected as part of the job? Could there be risks to interviewers' reputations (and livelihoods), for example, if the secondary analyst chose to criticise their interviewing techniques?

In the Family Lives and the Environment study, arrangements for collaboration with the Young Lives team are written into the data access agreement, and draft outputs using Young Lives data are discussed with the Young Lives team in Oxford, prior to publication or wider circulation. With the example given above, the Young Lives team imagined a fieldworker reading a narrative analysis of her introduction to the interview. Might she feel judged? Might she feel offended at a potential implication that she is setting out her difference or professional status relative to the participant?

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<sup>9</sup> Young Lives has ethics approval to voice-record the consent process, so that people do not have to sign a form (see Morrow 2009).

Through a collaborative discussion of these concerns, it was possible to reach a consensus – to take account of the constraints and expectations under which Young Lives fieldworkers operate, whilst retaining the narrative focus and objectives of the Family Lives and the Environment study.

This discussion is crucial because of the manifold distances between UK researchers and fieldworkers and participants in India. When working from transcription, there are many aspects of co-construction – including body language and facial expression – that cannot be taken into account from an interview transcript or an audio file. Translation adds another layer of complexity. Within Young Lives primary data analysis, the Oxford team frequently return to fieldwork teams to ask for clarification, and confer about interpretations and understandings. The Family Lives and the Environment team has been in an unusual position as secondary analysts, in having had access to rich data gathering reports, along with support and guidance from the Oxford and India qualitative teams. This has been possible only because established links between the teams (and Morrow and Boddy in particular) enabled a formal collaboration, with costed input from the Young Lives team into the NOVELLA Node. This framework has deepened mutual understanding between the two research teams, benefiting substantive understandings on both sides, as well as ethical practice.

Studies like Young Lives raise specific questions about consent because of their longitudinal nature. In Young Lives, consent is sought repeatedly through the research process, and the right to withdraw is made clear at each round (see Morrow 2009, 2013). In the context of secondary analysis for the Family Lives and the Environment study, it has also been important to recognise that research relationships – with participants *and* local fieldwork teams – are ‘live’, with new rounds of data collection being planned as we write. The risks from problems caused in re-use are of a different order in an ongoing study: any problems caused by data sharing could jeopardise those research relationships, and future work in an ongoing study.

In the context of a secondary analysis such as in the Family Lives and the Environment study, there are potential reputational risks to both research teams. For the Young Lives study, there could be potentially deleterious effects on field teams and research relationships, if papers are produced that misinterpret or criticise fieldwork practices or cultural contexts for data collection. At the same time, there are reputational risks for the FLE secondary analysts, reading transcripts from a different theoretical lens. With all the caveats about contextual distance noted above, how does the secondary researcher retain her analytic independence, when a difference in interpretation could be taken to imply that the secondary analysis is failing to understand context, simply getting it wrong, or co-opted to the primary researchers’ perspectives? Communication and a collaborative ethos from *both* sides are essential to ensure that data sharing can achieve its potential value.

## **What’s in a name? Anonymisation and anonymity**

The limits of anonymisation have increasingly been recognised in relation to biobanking and DNA data, as developments in information technology and potential for data linkage make it less feasible to guarantee true anonymity (Nuffield 2012). In qualitative research, questions of anonymisation are equally troubled. The UK Data Archive (2011)<sup>10</sup> recommend that, to avoid the lengthy and resource-intensive process of anonymising data after they have been collected, researchers should agree with

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<sup>10</sup> <http://data-archive.ac.uk/create-manage/consent-ethics/anonymisation?index=2>

participants that names should not be mentioned during the interview. These guidelines also suggest that this should extend to other personal identifiers: 'names of friends, relatives, places, institutions...'. But what might this look like in practice?

In Young Lives – as in any study where participants are asked to talk about their lives – children and adults frequently name important people and places in their lives. All of these could be used – especially in combination – to identify an individual or family. It is very common practice in speech to use real names. Skilled Young Lives fieldworkers work to establish rapport, using semi-structured interview guides loosely, so that interviews are 'conversations with a purpose' rather than formal structured questioning (Mayall, 2000). This can in itself be seen as ethical practice, particularly in the context of research with children; it is important not to make the interview conversation unnecessarily artificial. The need for the researcher to 'correct' participants' normal speech by reminding them not to use names or places would reinforce power differentials between researcher and researched: it could make participants feel like they are 'getting it wrong' and the sense of secrecy invoked could be alarming, especially for people who do not fully understand archiving.

Further, in many cultures, people use 'fictive' kin terms to describe people close to them. In India for example, 'auntie' may refer to older women in the community as well as father's or mother's sisters. Ideally the interviewer would seek clarification of the relationships involved, but to do so would interrupt the flow of conversations and be very time-consuming and distracting, so interviewers tend not to, and names are helpful for disentangling relationships. Names may also carry symbolic value for parents, children and others in the community, signifying important beliefs and links across generations and families. This is vividly illustrated in an anonymised extract from Young Lives, when the interviewer asks a parent why her son has a certain (biblical) name:

Interviewer: ... this is about your child, Child ID. Who does give him this name?  
Caregiver: It's me  
Interviewer: Why did you call Child ID Child ID?  
Caregiver: It is a Bible name.  
Interviewer: Now and for the future does he is going to work like NAME in the Bible?  
Caregiver: As you know NAME works good things in front of God.  
Interviewer: Do you think he will be good and strong man like NAME?  
Caregiver: Why we name the child is that his aunt's name is also NAME. ... It is a good name, so we called him Child ID.

This brief extract shows the symbolic importance of the child's name for the parent. But it also shows that it is not straightforward to anonymise names and retain meaning. Pseudonymisation would be no easier, as it would depend on finding a culturally appropriate name which also signifies someone 'good and strong' in the Bible.

The UK Data Archive guidelines suggest agreeing with participants in advance which names should not be disclosed during an interview, but questions have also been raised about how this might distort the process of qualitative research. Mauthner (2012, p166) points out, listening to someone carefully involves using information and details already provided during an interview, and this might well include people's names, 'partly to generate further questions and narratives... it involves developing a relationship'. To remind participants not to use real names means that the *primary*

data collection is designed to serve the *secondary* use. This is ethically (and methodologically) problematic: it is effectively a requirement for self-censorship that could make participants feel uncomfortable and distort the interview process. This is especially relevant in contexts – including research with children – where power relationships with adult researchers need to be taken into account. Participants might feel they are ‘getting it wrong’ if they mention a name; they could feel researchers are telling them off or telling them what to say or what not to say. Are these risks justifiable, to facilitate anonymisation and data sharing?

## Conclusion

Our experience of working together on data from Young Lives has highlighted the value of data sharing, for both primary and secondary research teams. For the secondary researchers in the Family Lives and the Environment team, the richness of the Young Lives qualitative data was an invaluable introduction to understanding the everyday lives of children and families in Andhra Pradesh. It was pivotal to subsequent theoretical and methodological development for the project, particularly in planning new data collection in India and the UK, including a new research collaboration with Young Lives researchers in India (Uma Vennam and Madhavi Latha).

For the Young Lives team, the collaboration has illuminated the complexities of data sharing, clarifying the considerations and safeguards that would need to be taken into account if the Young Lives qualitative data were to be archived (for example, in relation to the tension between anonymisation and contextual understanding). It has also enabled understanding of what different analytic approaches can bring to the Young Lives data, particularly through the case-based narrative approach adopted by the FLE team (see Shukla et al. 2014; Boddy 2014). Such learning is also valuable in planning future collaborations on secondary analysis of Young Lives qualitative data.

For both teams, the research has also shown the particular potential of applying a narrative secondary analysis to an existing data set, illuminating the complexities, dynamism and tensions inherent in young people’s everyday lives in relation to their environments:

Identities come to life and are re-enacted through the told stories of the interview conversation, illuminating children’s mobility and navigation of everyday spaces within the constraints of their daily lives. (Shukla et al. 2014, p22)

However, the enterprise of sharing qualitative data is not straightforward. Data sharing is a relational process, raising ethics questions that need consideration (Mauthner and Parry 2013). From research design to the publication and dissemination of findings, the research enterprise is quintessentially about relationships – relationships between participants and fieldworkers, fieldworkers and coordinating research teams, and with colleagues with whom we share our data and experiences. Over the course of the collaboration discussed here, there was a point at which we realised we needed to trust each other, and our intentions for the data and the secondary analysis process. It was not difficult for us to reach this point because time for collaboration and communication was funded within the research design, and some of us (VM and JB) have known each other for a long time, and worked and written together in the past.



The wider challenge is to understand how this experience might translate to another research context, to establishing mutual trust and respect in a 'stranger' analysis of someone else's data. Secondary analysis for the Family Lives and the Environment project was complex in several respects because of our multiple distances from the data (geographic, temporal, cultural, linguistic and epistemological), and so trust and communication were particularly important, to ensure understanding (on all sides). But the lessons we have learned, the risks discussed here, and the strategies we developed to counter those risks are relevant to any qualitative secondary analysis.

Of paramount importance was the time taken by the FLE team to learn about the Young Lives study (its objectives, methodology and data collection practices) and also to share information with Young Lives researchers about the FLE and NOVELLA projects. This collaborative process was central to the effective (and ethical) conduct of the work. It helped the FLE team to understand the Young Lives data they were working with – including what was being asked, by whom, and for what purpose – and so to become aware of the limits of their understanding. It also helped the Young Lives team to see their data from a different perspective, the 'macro-zoom' close-up entailed by narrative analytic reading for the FLE study. Discussion of analyses, and time spent reading cases together, helped to familiarise researchers from each team with the other team's approach – and this joint work in itself has illuminated the value of combining narrative and thematic analytic approaches (Shukla et al. 2014).

The process of contextualisation and discussion also allowed relationships and trust to build between the Young Lives and FLE research teams. The Young Lives team needed to be confident that they could trust the FLE researchers to understand and (re)use their data – especially given that the data are not publicly archived. The FLE team needed to be confident that they could understand (and hence work with) Young Lives data, but beyond that, it was important that the Young Lives team understood the distinct objectives and approach of the FLE project. For example, by discussing the attention to co-construction in our narrative analysis we could address potential concerns from the Young Lives research team about the focus on interviewers' own talk. By sharing draft outputs, the FLE team could avoid misinterpretations of data, whilst the development of joint understandings of the methodological approach and objectives of *each* project helped to avoid Young Lives researchers' misinterpretations of the FLE team's work. Secondary analysis is sometimes seen as a (relatively) cheap solution to the challenge of funding social science research. In our research, costing Young Lives input into the secondary analysis was crucial in enabling the time and joint work that was necessary to build a mutual understanding.

The pressures on social science researchers to archive their data are now very great indeed, and it is important that *economic* imperatives for data re-use are recognised for what they are (and as distinct from *ethical* imperatives). Data sharing is potentially very valuable, for all of the reasons that Van den Eynden et al. (2011) and others have outlined, reasons that include (but are not restricted to) cost. However, the sharing and re-use of data is ethically complex and must be addressed with regard to 'our ethical and moral responsibility as researchers' (Mauthner 2012, p173). We face these ethical and moral responsibilities as primary *or* secondary researchers, or somewhere on a spectrum between the two.

Since data sharing is seen as the 'default' approach by funders such as the Research Councils, researchers could neglect the complex ethics considerations involved in this aspect of the research

process. This positioning risks leaving researchers – both those who share their data and those who engage in secondary analysis – ill-equipped to deal with ethics considerations such as those outlined above.

For studies that plan to archive and share their data, *and* studies that plan to re-use other researchers' data, there are practical considerations that need to be addressed, and these have implications for the time and expense necessary for the work. For example, primary researchers need to consider what is involved in ensuring appropriate (informed) consent for uncertain future uses, and to ensure the necessary resources to prepare qualitative data for archiving. Secondary researchers need to ensure sufficient contextualisation to avoid risks of mis-representation, but also have responsibilities to ensure that their planned (re)uses accord with original consents and understandings by participants. Anonymisation remains a critical issue for both primary and secondary analysts. Strategies for anonymising data in the course of its collection (such as reminding participants not to mention identifying aspects of their lives) could jeopardise primary data quality for the sake of future possible uses, whilst raising ethical concerns of their own. Equally, full anonymisation inevitably de-contextualises qualitative data, *because* of the removal of identifying details such as place or distinctive participant characteristics, and this creates risks of misinterpretation for the secondary analyst. Such concerns are not insurmountable, but they do require reflection, planning and resourcing, as with any other area of ethical research practice.

In an ongoing study such as Young Lives, 'live' responsibilities – to participants, fieldworkers and co-researchers, and the primary funder – must surely take precedence over obligations to wider (and potential future) research users. But in *any* study, secondary researchers must be cognisant of the concerns and responsibilities of the primary team, recognising the emotional labour of the original work (Neale and Bishop 2012). But equally, if primary researchers agree to share their data, they must do what they can to ensure that any new work can be done well. As Neale and Bishop (op.cit. no page numbers) advise:

'Secondary analysts have their own integrity, which is founded on intellectual rigour. They need well-produced and fully contextualised datasets to work with; they need to be free to ask their own research questions of the data, engage in distinctive modes of analysis; and produce their own interpretations, even where these run counter to primary understandings. The work of secondary analysts is best seen as an enhancement of primary research rather than a challenge or threat to it, and the endeavours of data re-use deserve respect and support from the primary researcher. In other words, for QL research, where both primary and secondary use may be ongoing, the ethic of care needs to run in both directions'.

Secondary analysis of qualitative data cannot be done in isolation: it requires a contextualised understanding that depends on mutual respect and collaboration between the primary and secondary research teams. The work reported here describes a funded collaboration, working together on data that are not publicly archived. Despite the complications and sensitivities we have outlined, both Young Lives and NOVELLA teams feel they have benefited greatly from the joint work we have done. Even when data are publicly archived – and when a formal funded partnership such as that described here is not possible or not appropriate – the spirit of mutual respect and collaboration which has guided our work is no less relevant. The considerations discussed here – responsibilities to participants and researchers, contextual understanding, how to identify and

counter risks of misinterpretation – will form a useful basis for planning and reflection in any qualitative secondary analysis, aiding both ethical research practice and the rigour, quality and integrity of both primary and secondary research.

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**NOVELLA**, Narratives of Varied Everyday Lives and Linked Approaches, is a research study concerned with the everyday habitual practices of families. It is an ESRC funded National Centre for Research Methods node 2011-14.

### **NOVELLA's six projects are**

Parenting Identities and Practices  
Families and Food  
Family Lives and the Environment  
Possibilities for a Narrative Analysis of Paradata  
Paradata  
Recipes for Mothering  
Advancing Paradata

### **NOVELLA also conducts**

Training and Capacity Building

### **Further Information**

Novella is based at the Institute of Education, University of London and collaborates with the Centre for Narrative Research, University of East London, Young Lives at Oxford University and the University of Sussex.

Please visit [www.novella.ac.uk](http://www.novella.ac.uk) for more information.

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