FULL/LONG TITLE OF THE STUDY

Tired of Spinning Plates: an exploration of the mental health experiences of adults/older carers of adults with learning disabilities (NIHR135080)

SHORT STUDY TITLE / ACRONYM

Spinning Plates: mental health and carers of adults with learning disabilities

PROTOCOL VERSION NUMBER AND DATE

- 0.1

RESEARCH REFERENCE NUMBERS

IRAS Number:	NA
SPONSORS Number:	177109
FUNDERS Number:	NIHR135080

SIGNATURE PAGE

The undersigned confirm that the following protocol has been agreed and accepted and that the Chief Investigator agrees to conduct the study in compliance with the approved protocol and will adhere to the principles outlined in the Declaration of Helsinki, the Sponsor's SOPs, and other regulatory requirement.

I agree to ensure that the confidential information contained in this document will not be used for any other purpose other than the evaluation or conduct of the investigation without the prior written consent of the Sponsor

I also confirm that I will make the findings of the study publicly available through publication or other dissemination tools without any unnecessary delay and that an honest accurate and transparent account of the study will be given; and that any discrepancies from the study as planned in this protocol will be explained.

For and on behalf of the Study Sponsor:		
Signature: D Lodge		Date: 03/08/22
Name (please print): Deborah Lodge		
Position: Director of Research Services		

Chief Investigator:		
Signature: Katherine Runswickcole		Date: 03/08/22
Name: (please print) KATHERINE RUNSWICK-COLE		

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STUDY SUMMARY

Carers talk about the satisfaction and joy they take in their caring relationships, but they also experience many practical difficulties which can affect their mental health (DoHSC, 2018). Research shows a link between being a carer and poor mental health (DoHSC, 2018). Pre-pandemic, carers of adults with learning disabilities made up a quarter of the 9 million carers in the UK (DoHSC, 2018) but we know little about their mental health, their access to services and support, and what they think good support looks like at different times in their lives. In addition, there appears to be no published research about the use of anti-depressant and anti-anxiety medication by family carers. NICE guidance on supporting adult carers (2020) briefly considers the mental health of adult carers of people with learning disabilities, but none of its research recommendations focus on the mental health of this group of carers.

The aim of this project is to better understand the mental health of carers of adults with learning disabilities and the support they need. We will use the findings of the project to develop teaching and learning resources for health and care practitioners (GPs, allied health professionals, social workers, support providers, and voluntary organisations, including carer-led organisations and self-advocacy groups of people with learning disabilities) to better understand and support carers' mental health.

We will find out about:
- the mental health issues of carers of adults with learning disabilities.
- their experiences of support and services, how good they believe they are and how easy they find them to access.
- what carers think about how support could be improved.

Study Title	Tired of Spinning Plates: an exploration of the mental health experiences of adults/older carers of adults with learning disabilities (NIHR135080)
Internal ref. no. (or short title)	Spinning Plates: mental health and carers of adults with learning disabilities

Study Design	Phase One: Spinning Plates group of carers and people with learning disabilities that will guide the research design and delivery as well as drawing on their lived experience (13 meetings) Phase Two: Literature Review Phase Three: survey design workshops (x2) and survey dissemination Phase Four: 24 narrative interviews Phase Five: 2 x digital storytelling workshops to create 24 x 2–3-minute short films (digital stories) Phase Six: findings synthesis to produce learning and teaching materials Phase Seven: dissemination phase, including end of project event and two roundtables.
Study Participants	Two groups of participants 1. carers of adults with learning disabilities 2. people with learning disabilities
Planned Size of Sample (if applicable)	Phase One: 9 participants Phase Three: 6 workshop survey design participants + 300 survey participants Phase Four and Five: 24 participants Phase Six: 9 participants - same participants as phase One
Follow up duration (if applicable)	NA
Planned Study Period	1st October 2022 - 30th November, 2024
Research Question/Aim(s)	The research aims (RAs) to:

	1. Address the gap in knowledge about how carers of adults with learning disabilities conceptualise and experience mental health across the life course; 2. Address the gap in knowledge about the perceived quality, accessibility and effectiveness of support for carers' mental health; 3. Explore the provision and uptake of support services, including barriers to accessing carers' support services, including marginalised communities and groups; 4. Explore carers' perspectives on the effectiveness of interventions for carers (including: respite; medication; social prescribing; passport schemes; employment support; alternative and complementary therapies); 5. Explore the long-term impacts of the COVID-19 pandemic on carers' mental health; 6. Co-produce the project, generate new knowledge and share impactful solutions working with groups of carers as co-researchers, research participants and project advisors.

FUNDING AND SUPPORT IN KIND

FUNDER(S) (Names and contact details of ALL organisations providing funding and/or support in kind for this study)	**FINANCIAL AND NON FINANCIAL SUPPORT GIVEN**
National Institute for Health and Social Care Research	

ROLE OF STUDY SPONSOR AND FUNDER

The University of Sheffield is the sponsor. The sponsor (HRA, 2022) has overall responsibility for the research, including:

a) identifying and addressing poorly designed or planned research and poor-quality research proposals, protocols or applications and ensuring that research proposals and protocols:
- take into account systematic reviews of relevant existing research evidence and other relevant research in progress,
- make appropriate use of patient, service user and public involvement and
- are scientifically sound (e.g., through independent expert review)

b) satisfying itself that the investigators, research team and research sites are suitable;

c) ensuring that roles and responsibilities of the parties involved in the research and any delegation by the sponsor of its tasks are agreed and documented;

d) ensuring adequate provision is made for insurance or indemnity to cover liabilities which may arise in relation to the design, management and conduct of the research project; and

e) ensuring appropriate arrangements are made for making information about the research publicly available before it starts; agreeing appropriate arrangements for making data accessible, with adequate consent and privacy safeguards, in a timely manner after it has finished; and ensuring arrangements for information about the findings of the research to be made available, including, where appropriate, to participants.

f) ensuring that the research has approval from a research ethics committee and any other relevant approval bodies before it begins;

g) verifying that regulatory and practical arrangements are in place, before permitting the research to begin in a safe and timely manner;

h) putting and keeping in place arrangements for adequate finance and management of the research project, including its competent risk management and data management;

i) ensuring that effective procedures and arrangements are kept in place and adhered to for reporting (e.g. progress reports, safety reports) and for monitoring the research, including its conduct and the ongoing suitability of the approved proposal or protocol in light of adverse events or other developments (NHS, HRA, 2022)

Following NHS HRA guidance (2022) the funder is responsible for:

a) assessing (or arranging for assessment of) the scientific quality, the relevance of the research to the target population and, if appropriate, the value for money of the research as proposed, involving patients, service users and the public where appropriate in funding decisions;

b) reviewing information about the attribution of costs to confirm that costs to all parties (including excess treatment costs) have been identified and described in accordance with national guidance and that the costs are not disproportionate compared to the value of the output;

c) considering (with advice if necessary) whether the research is really achievable within the settings as a whole in which it is intended to be carried out, particularly in view of the priorities and constraints in health and social care if the research will have an impact on care provision;

d) making ongoing funding conditional on a sponsor and relevant approvals being in place before the research begins (but not before initial funding is released, as some funding may be needed in order to put these in place); and

e) using contracts for making information about research publicly available before it starts (unless a deferral is agreed by or on behalf of the research ethics committee) and for retaining and making accurate findings, data and tissue accessible, with adequate consent and privacy safeguards, in a timely manner after it has finished.

ROLES AND RESPONSIBILITIES OF STUDY MANAGEMENT COMMITTEES/GROUPS & INDIVIDUALS

The Study Steering Committee: the steering committee will meet four times (once f2f and 3 x online) during the project to provide overarching strategic guidance and scrutiny that is independent of the investigators. The Study Steering Committee will be chaired by Rohit Shankar MBE, Professor in Neuropsychiatry at the University of Plymouth Medical School, Director of Cornwall Intellectual Disability Equitable Research Unit. He has national/international awards including the BMJ award for mental health (2020). Steering committee members will include: Katie Clarke, Bringing Us Together (PPI independent member); Lynn James-Jenkinson, Pathways Associates (PPI independent member); Ramandeep Kaur, parent-carer (PPI independent member); Liz Wilson, family-carer (PPI independent member); Dr Hannah Morgan, Associate Professor of Disability Studies and Social Policy, The University of Leeds (independent member); Professor Sara Ryan, Joint Lead Investigator (member) Professor Katherine Runswick-Cole, Lead Investigator, The University of Sheffield (member). Costs have been sought to meet travel, accommodation, subsistence, and access requirements.

Patient & Public Involvement Group

The "Tea, Cake and Spinning Plates" group (hereby Spinning Plates Group) will meet 13 times (online and/or face to face) with provision for catch up meetings in smaller groups or one-to-one where this meets the requirements of group members. This group will be made up of 6 carers of adults with learning disabilities and 3 people with learning disabilities. The purpose of this group is to act as an innovative hybrid of traditional PPI for the study. Following a traditional model of PPI, the group will provide guidance, feedback, and advice on each phase of the research. However, the group will act as co researchers and the regular group discussions about the research design, delivery and dissemination will form part of the project dataset. We have taken this approach as members will inevitably draw upon their own experiences of mental health across the life course to reflect on the on-going research and we want to capture these rich reflections to inform our research. The Spinning Plates group will work together to develop and agree the terms of reference for the group. This will include deciding how the meetings will be run, planning for shared decision making, agenda setting and establishing a distress protocol for discussions of difficult topics. We have planned for flexible participation in this group. So, for example, members may not wish to or be able to attend every meeting of the group but could choose to be kept in touch with updates from the meeting via email, phone calls or via a catch up with a member of the research team. A co-authored diary will be kept throughout the project and group members, who wish to, will be included as co-authors on research outputs.

PROTOCOL CONTRIBUTORS

The research leadership team brings together a group of experienced collaborators with specific expertise.

Lead applicant, Professor Katherine **Runswick-Cole** (University of Sheffield) has extensive experience of co-producing research with people with learning disabilities and their families and of hybrid online and face-to-face research methods (ESRC-ES/K004883/1; ESRC-ES/P001041/1; NIHR202996). Runswick-Cole will co-lead the project with Ryan to ensure that the project is completed on time and on budget. Runswick-Cole will supervise and mentor the PDRA and support their development following the *Concordat to Support the Career Development of Researchers* (Vitae, 2019). She will oversee all aspects of the project. On confirmation of funding, Runswick-Cole will submit the ethics application. Runswick-Cole also brings her lived experience as the carer of an adult son with learning disabilities.

Joint lead applicant, Professor Sara **Ryan** (Manchester Metropolitan University) has extensive experience of working with carers and people with learning disabilities and of using on-line and narrative methods (NIHR 129491; NIHR 12861). In addition to her co-leadership role outlined above, Ryan is PPI lead. As PPI lead, Ryan will lead the development of the project's overall PPI strategy. She will guide the co-applicants, PDRAs and Spinning Plates group in their delivery across the research phases. She will ensure that every stage of the project is conducted guided by the principles of inclusion and participation to ensure that all stakeholders can engage fully and equally. Specifically, she will: convene and co-chair the Spinning Plates group; liaise with participant co-researchers and with co-applicants throughout the project and report to the Study Steering Committee on matters pertaining to PPI and EDI.

Co-applicant, Dr Patty **Douglas** (Associate Professor, Canada) (Brandon University, Canada) brings a unique methodological approach, not available in the UK, in leading on the creation of on-line digital stories, building on her work funded by the Social Sciences and Humanities Research Council, Canada (SSHRC-435-2019-0129). She also brings her extensive experience of working with marginalised communities in Canada. She will contribute to written outputs. Patty is also a carer of an adult with learning disabilities.

Co-applicant, Professor Chris **Hatton** (Manchester Metropolitan University) brings extensive experience of NIHR funded projects (NIHR 200069) and is Co-PI of the UKRI/NIHR Coronavirus and People with Learning Disabilities Study (COV0196), which includes online surveys with family carers and support workers. He will lead on survey design and analysis and contribute to outputs.

Co-applicant - PPI, Dr Rosamaria Kostic **Cisneros** (RosaSenCis Productions) has extensive experience of digital technologies, the arts and cultural heritage. She will play an active role as a member of the research team, offering supporting recruitment and Equality Diversity and Inclusion (EDI)

Co-applicant, Dr Liz **Croot** (The University of Sheffield) is an academic and physiotherapist with experience of working with parents of disabled children from South Asian communities. She will play an active role as a member of the research team supporting recruitment and EDI.

Co-applicant - PPI, Clare **Kassa** is a sibling carer and Chief Executive of Sibs, the UK's leading charity for brothers/sisters of disabled children/adults. Clare will play an active role as a member of the research team by advising on research design and supporting participant recruitment, dissemination and supporting EDI.

PDRA (Grade 7.3) (100% FTE) will work under the supervision of the Lead Applicants to facilitate all research activities and contribute to outputs. Runswick-Cole will act as lead mentor to the PDRA, supported by the Joint Applicant and Co-applicants who will offer their specific expertise in line with the Concordat to Support the Career Development of Researchers (Vitae, 2019).

PPI Involvement

The idea for this project first started to emerge at a digital storytelling workshop held with parents and carers of people with learning disabilities and/or autism in Toronto in 2019, led by Douglas (co-applicant) and Runswick-Cole (Lead Applicant). This led to a small project supported by the University of Sheffield and the Re*Storying Autism project, funded by the Social Sciences and Humanities Research Council based at Brandon University, Canadian which carers from Canada and from the UK described the mental health challenges they faced, the lack of what they felt was appropriate and accessible support and the general lack of awareness of the challenges they experience. For this application, we approached individual family carers, carer organisations (Bringing Us Together, Sibs), and self-advocacy groups (Sunderland People First, Pathway Associates) to support the development of this bid. This process of consultation has had tangible impacts on the development of the project including one family carer generating the project title of 'Spinning Plates'. In addition, the decision to offer separate storytelling workshops for parent carers from sibling carers was in response to sibling carers' suggestion that this would support their participation. Discussion also led to the inclusion of people with learning disabilities on the steering group in order to ensure that the views of adults with learning disabilities are not marginalised in the project. Clare Kassa from Sibs agreed to become a co-applicant and members of Bringing Us Together, and Pathways Associates will sit on the Study Steering Group.

KEY WORDS:	carers; adults with learning disabilities; mental health; co-production; participation; digital storytelling

STUDY FLOW CHART

		Months							
Phases	**SMART Objectives**	**0**	**1-4**	**5-8**	**9-12**	**13-16**	**17-20**	**21-24**	**25-26**
Ethics application	Completion of ethics application to TUOS and HRA (as soon as funding is confirmed).	🟩							
Phase One: PPI "Spinning Plates, Tea, Cake and Chat"	RO1: To convene a "Tea, Cake and Spinning Plates" Group which will act as the study PPI group and co researcher group (13 meetings);		🟩	🟩	🟩	🟩	🟩	🟩	🟩
Phase Two: Literature Review	RO 2: To publish a rapid literature review on the mental health of carers of adults with learning disabilities Output: Report (6,000 words) + summary document		🟩						
Phase Three: Survey Workshops	RO3: To co-design and conduct a survey with up to 300 carers to explore their experiences of mental health and support; Output: Survey findings (4,000 words) + summary document for participants			🟩	🟩				
Phase Four: Online Interview Study	RO4: To conduct 24 interviews and with carers to create new narratives of carer mental health; Output: Report (8,000 words) summary document for participants			🟩	🟩				

Phase Five: Online digital storytelling workshops	RO4: To conduct 2 x online storytelling workshops with 2 x 12 carers (n=24) to create new narratives of carer mental health Output: 24 digital stories of carers' mental health shared with participants, including transcripts					🟩	🟩		
Phase Six: Synthesising Findings; Creating Resources	RO5. To synthesise findings and to generate teaching and learning resources for GPs, allied health professionals, social workers, support providers, and voluntary organisations, including carer-led organisations and self-advocacy groups of people with learning disabilities, mental health commissioners to improve support for carer mental health. Outputs: teaching and learning materials			🟩	🟩	🟩	🟩	🟩	🟩
Phase Seven: Dissemination	RO6. To disseminate research findings via: an end of project event; two round tables; screening of films via healthtalk.org and socialcare.org & submit 3 peer review journal articles for publication based on the findings. 1 article for *Community Care Magazine.*							🟩	🟩
				*		*		*	
Progress Compliance Reports				*		*	*	*	*
Research Management Meetings			*****	****	****	****	****	****	****
Study Steering Group Meetings			*	*		*		*	*

STUDY PROTOCOL

Tired of Spinning Plates: an exploration of the mental health experiences of adults/older carers of adults with learning disabilities (NIHR135080)

1 BACKGROUND

Carers talk about the satisfaction and joy they take in their caring relationships, but they also experience many practical difficulties which can affect their mental health (DoHSC, 2018). Research shows a link between being a carer and poor mental health (DoHSC, 2018). For example, mothers, fathers and siblings of disabled children all experience poor mental health (Rydzewska et al., 2021; Dunn et al, 2019; Caliendo, et al., 2020; Sibs, 2018) as do carers of older people and carers of people with dementia (NHS, 2017, Carers UK, 2019). Pre-pandemic, carers of adults with learning disabilities made up a quarter of the 9 million carers in the UK (DoHSC, 2018) but we know little about their mental health, their access to services and support and what they think good support looks like at different times in their lives. Recent research has also revealed the reduction in support offered to carers of adults with learning disabilities as a result of funding cuts (Forrester-Jones, 2021a) and the challenges that carers face as they move towards retirement age (Forrester-Jones, 2021b). The COVID-19 pandemic has magnified the challenges faced by carers of adults with learning disabilities. For some carers, the reduction or cessation of support services for adults with learning disabilities has led to them providing urgent additional support (Patel et al., 2021). For other carers, COVID control procedures mean that they have been stopped from seeing their loved ones which has caused considerable distress (Patel et al., 2021; Sibs, 2021). Despite these challenges and, perhaps, because of a narrow evidence base, NICE guidance on supporting adult carers (2020) continues to be limited in its consideration of the mental health of adult carers of people with learning disabilities. None of its research recommendations focus on the mental health of this group of carers and there appears to be no published research about the use of antidepressant and anti-anxiety medication by family carers.

In line with the challenges identified in the NHS Long Term Plan (NHS, 2019), this research seeks to address the causes and effects of mental ill health in the lives of carers of adults with learning disabilities. Specifically, the project will explore carers’ perceptions of and access to mental health services and support with the aim of informing the development of mental health support as part of the COVID-19 pandemic recovery. We will do this by raising awareness of the mental health of carers of adults with learning disabilities among carers and among individuals and organisations that support them, including health and social care practitioners and the wider public. We will co-produce accessible learning and teaching materials to support better mental health for carers. This project is driven by a recognition of the enduring inequalities in access to high quality mental health services for carers of adults with learning disabilities. Our aim is for the research to remove the barriers to participation so that the research can be shaped by and reach people, communities and regions which have the greatest mental health care needs. The principles of equality, diversity and inclusion inform every part of the project from development of the bid itself to the design, delivery and dissemination of the research.

2 RATIONALE

The importance of informal care in bridging the gap between health and social care services has increasingly been recognised (DoHSC, 2018). It is crucial to understand carers' mental health and support needs in order to maintain and build mental wellbeing while they continue to care. And yet, concerns about carers of adults with learning disabilities' mental health are not always prioritised in carer research, policy and practice, which has often been dominated by a focus on post-diagnostic support for people with dementia and their carers (NHS, 2017). We need to generate new knowledge and understanding to meet the specific mental health needs of carers of adults with learning disabilities, and the cumulative impact of care over prolonged periods of time. We need to understand better how carers perceive the accessibility and quality of support available to ensure that the quality of mental health support for carers and for people with learning disabilities is high, enabling them to live flourishing lives. Research is beginning to reveal the initial impacts of COVID-19 on the mental health of carers of adults with learning disabilities (Patel et al., 2021; Sibs, 2021; Rogers et al., 2021), however, the impact of repeated lockdowns is not well understood. This timely research will seek to ensure that the mental health needs of carers of adults with learning disabilities are central to plans to 'build back better' health and social care (Cabinet Office, Department for Health and Social Care and Prime Minister's Office, 2021).

3 THEORETICAL FRAMEWORK

Our approach to understanding carers' mental health is guided by a social model of mental health. Traditionally, professional approaches to mental health issues have been medically based, seeing the problem as lying within the individual. A social model of mental health argues, instead, for a focus on the social determinants of mental health and a shift away from solely individualised responses and 'solutions' to focus on social as well as personal issues (Beresford et al., 2010; Douglas et al., 2021a). We argue that we need to understand the complexity of causes of mental distress reported by carers and the cumulative impacts of long-term care on mental health in order to build better support for wellbeing. Recent research has revealed that nearly half of all people living in poverty in the UK are disabled people or live with someone who is disabled (Oakley, 2021) and that there is a strong association between poverty and mental ill health (Delgadillo, 2018). This theoretical orientation guides our methodological approach. Historically, people who use mental health services have not been given meaningful roles in research about improving access to and the quality of the mental health care they receive (Case et al., 2014). In contrast, our approach is a collaborative one, drawing on the principles of participatory action research (PAR), which place the perspectives and knowledge of marginalised communities at the centre of research design and practice (Kemmis and McTaggart, 2008).

4 RESEARCH QUESTION/AIM(S)

The research aims (RAs) to:

1. Address the gap in knowledge about how carers of adults with learning disabilities conceptualise and experience mental health across the life course;
2. Address the gap in knowledge about the perceived quality, accessibility and effectiveness of support for carers' mental health;
3. Explore the provision and uptake of support services, including barriers to accessing carers' support services, including marginalised communities and groups;
4. Explore carers' perspectives on the effectiveness of interventions for carers (including: respite; medication; social prescribing; passport schemes; employment support; alternative and complementary therapies);
5. Explore the long-term impacts of the COVID-19 pandemic on carers' mental health;
6. Co-produce the project, generate new knowledge and share impactful solutions working with groups of carers as co-researchers, research participants and project advisors.

4.1 Objectives

The research aims will be met through the following research objectives (ROs):

1. To convene a “Tea, Cake and Spinning Plates” Group which will act as the study PPI group and co-researcher group;
2. To publish a rapid literature review on the mental health of carers of adults with learning disabilities;

3. To co-design and conduct a survey with carers to explore their experiences of mental health and support;
4. To conduct interviews and online storytelling workshops with carers to create new narratives of carer mental health;
5. To synthesise findings and to generate learning and teaching resources for GPs, allied health professionals, social workers, support providers, and voluntary organisations, including carer-led organisations and self-advocacy groups of people with learning disabilities, to improve support for carer mental health;
6. To disseminate research findings via an end of project event; two round tables; screening of films via healthtalk.org and socialcaretalk.org and through published materials.

Specific research questions (RQs) addressed through the research phases:

1. How do carers of adults with learning disabilities conceptualise and make sense of their own mental health across the life course?
2. What services, support and interventions do carers access (including: social prescribing; carers' passports; medication; talking therapies; peer support; alternative and complementary therapies) and how effective do they consider them to be?
3. What has been the impact of mental health issues on carers' family lives, ability to care, employment, friendship and social life?
4. What are the impacts of COVID-19 so far on carers' mental health, and how do carers perceive the medium and longer-term impacts and necessary support and interventions?
5. What do carers believe practitioners, providers and other organisations need to know and do to support carers?

4.2 Outcome

The project will increase the evidence base in relation to:

- how carers of adults with learning disabilities conceptualise and experience mental health across the life course;
- how carers perceive the quality, accessibility and effectiveness of support for mental health;
- the provision and uptake of support services, including barriers to accessing carers' support services, including marginalised communities and groups;
- carers' perspectives on the effectiveness of interventions for carers (including: respite; medication; social prescribing; passport schemes; employment support; alternative and complementary therapies);

○ understanding the long-term impacts of the COVID-19 pandemic on carers' mental health

○ generating new knowledge and sharing impactful solutions working with groups of carers as co-researchers, research participants and project advisors.

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5 STUDY DESIGN and METHODS of DATA COLLECTION AND DATA ANALYSIS

The study will take place over 26 months and across 7 research phases.

Phase 1: "Tea, Cake and Spinning Plates" group

This group will be made up of 6 carers of adults with learning disabilities and 3 people with learning disabilities. The purpose of this group is to act as an innovative hybrid of traditional PPI for the study. Following a traditional model of PPI, the group will provide guidance, feedback and advice on each phase of the research. However, the group will act as co researchers and the regular group discussions about the research design, delivery and dissemination will form part of the project dataset. We have taken this approach as members will inevitably draw upon their own experiences of mental health across the life course to reflect on the on-going research and we want to capture these rich reflections to inform our research.

Phase 2: Literature Review

In Phase 2, under the supervision of **Runswick-Cole and Ryan**, the **Post-Doctoral Research Associate (PDRA)** will conduct a rapid review to scope existing evidence about carers of adults with learning disabilities' mental health needs and the mental health support available (Tricco et al., 2018). The review will focus on the mental health of carers of adults with learning disabilities in relation to: the impact on the day-to-day lives of carers; knowledge of and access to support, including medication and talking therapies as well as complementary and alternative therapies such as: looking after physical health (sleep; exercise; healthy eating; alcohol use; personal care); creative therapies (music, arts, dance and drama); yoga; meditation; hypnotherapy, herbal remedies and acupuncture.

Phase 3- Survey Co-Design Workshops

Through two survey co-design workshops with family carers, we will develop an online structured survey to investigate priority issues for carers in terms of mental health. In the first co-design workshop family carers will prioritise the issues the survey should address. In the second workshop options for candidate questions addressing these issues will be discussed and a final set of questions decided upon.

Phase 4: Qualitative Interview Study (Online)

We will carry out 24 open-ended, semi-structured interviews. Interviews will be held in advance of 2 storytelling workshops to generate evidence of the experiences, perspectives, and knowledge of carers (parents and siblings) of adults with learning disabilities across the life course. The interview guide will be informed by findings from the literature review and survey and will be co-designed with family carers and people with learning disabilities in the Spinning Plates group

Phase 5: Online Digital Storytelling Workshops

We will hold two online digital storytelling workshops with 12 participants at each (n=24). Following consultation with carer organisations, there will be a separate workshop for parent carers and one for sibling carers to create safe places for participants to share their stories. Workshops will take place online over 4 weeks. Workshops will provide participants with training in digital storytelling (video editing in WeVideo, storyboarding, capturing video, etc.), as well as artistic and technical support in whole group, small group and 1-1 sessions to produce short films about their experiences.

Phase 6: Synthesising Findings; Creating resources

We will draw together findings from the survey, interviews, digital stories and research journal. We will develop “Spinning Plates” learning and teaching resources for: GPs, allied health professionals, social workers, support providers, and voluntary organisations, including carer-led organisations and self-advocacy groups of people with learning disabilities. In addition, we will produce tailored learning and teaching materials for mental health teams and commissioners. These will be published, with the digital stories, on Healthtalk.org and Socialcaretalk.org.

Phase 7: Dissemination

We will hold an end of project event for carers and practitioners, including a screening of the digital stories, which will also be shared online and promoted via social media. In addition, we will hold two round table discussions. Invitations will be based on the people/organisations who are identified as important actors throughout the project, including GPs, social workers, commissioners, family carer organisations, self-advocacy groups, and allied health professionals. We will also disseminate findings via Learning Disability Partnership Boards and Integrated Care Boards. In addition to these resources, 3 peer reviewed journal articles will be published, based on the findings from Phases 1-5 and analysis of digital stories.

Data analysis

In **Phase One** analysis will form part of the discussion in each of the meetings. The notes, and diary entries recorded in the meetings will be coded in Nvivo using a modified framework approach (Gale et al., 2013). While framework analysis is not usually allied to an interactionist approach, it is a flexible tool which is adaptable and accessible for co-researchers with developing qualitative research skills. A matrix of codes will be produced and discussed at the subsequent meetings with the Spinning Plates Group. Our aim is to capture the micro-detail in which people express their experiences, both positive and negative, while reflecting on what is happening and making sense of their everyday experiences. **Phase Two** the narrative synthesis of the literature is described above. **Phase Three** quantitative data will be exported from Qualtrics into SPSS. Data analysis will be largely descriptive, with medications analysed using the Anatomical Therapeutic Chemical classification system. Between-group differences (e.g.: mental health by carer gender) will be examined using chi-square and Relative Risk Ratios, and associations (e.g.: between carer mental health and carer age) will be conducted using correlations and, where appropriate, multiple regressions. Open-ended survey questions will be analysed using qualitative content analysis to develop themes in the data. The interview data collected in **Phase Four** will be transcribed and the data will be analysed thematically using Invivo coding. Invivo coding is a qualitative data analysis approach that uses participants' own words to develop codes and aligns with a commitment to co-production (Leavy, 2017; Strauss, 1987). We will ensure quality in our qualitative interview design by following the eight "big tent" criteria for excellence forwarded by Tracy (2010). The data will be translated into mind maps to allow us to generate themes, make links, identify and visualise the data in different ways. Co-researchers will not be directly involved in the stages of analysis detailed above; recent research advises that people should not be asked to look at large amounts of text (Locock Crocker et al., 2017). However, summary codes and mind maps will be used to stimulate discussion at the Spinning Plates group and will develop and extend the emerging analysis.

The films generated in **Phase 5** will be analysed at two screening events. Following an approach developed by Douglas (Douglas et al., 2019) the participant film makers and the research team will collaboratively identify themes and understandings emerging from the films through a process of discussion. The films will also be shared with the Spinning Plates group to further extend the analysis.

This open approach to analysis reflects the value we attach to the power of storytelling to illuminate and enrich understandings of lived experience in health research (Frank, 2010).

Transcription

Transcription will be carried out by a transcription service. Prior to the sharing of any transcripts, we will alert the transcriber to the potentially sensitive nature of the content and will share the safeguarding protocol for transcribers with them. We will also ask them to sign a confidentiality agreement to protect the anonymity and confidentiality of participants.

De-identification

Data will be de-identified at the earliest opportunity. Data relating to individual participants will be assigned a unique identifier. The identifier key will be stored separately and securely on the relevant password protected university network.

If participants agree that they would like video/audio extracts from their interviews used in study outputs, then we will discuss the benefits and risks of this with all participants. If participants choose to be de-identified then all efforts will be undertaken to achieve this. For example participants will be invited to choose an alias if they do not want to use their own name and locations and other personal details will be changed. Voice and face modulation will be applied where necessary to any outputs and stored data. Other written outputs will include direct quotes, but these will not be traceable to specific individuals.

- **Phase One - discussion groups and diary entries:** research notes and diary entries will include the real names of participants – these will be anonymised and pseudonymised by the PDRA and/or other members of the research team as soon as possible and recordings deleted.
- **Phase Three - design workshops:** research notes will include the real names of participants – these will be anonymised and pseudonymised by the PDRA and/or other members of the research team as soon as possible and audio recordings deleted.
- **Phase Three - survey:** survey data will be anonymous
- **Phase Four** - **interviews**: interview transcripts will be anonymised and pseudonymised by the PDRA and/or other members of the research team
- **Phase Five - digital stories:** digital stories will be pseudonymised and anonymised in consultation with participants and members of the research team. We have included an additional film release form so that we can be sure that participants are happy for their film to be published. In stories where other people not involved in the research are identifiable, we will also ask them to sign a release form before publication.

- **Phase Six - findings synthesis:** research notes will include the real names of participants – these will be anonymised and pseudonymised as soon as possible and recordings deleted by the PDRA and/or other members of the research team.

Access

Access to the recording of the interviews/ discussion workshops will only be shared with members of the research team as necessary. Data and the analysis will be backed daily on a password protected document on the University of Sheffield server for WPs 1,2,4,5,6 and MMU server for WP3.

Where data needs to be transferred between members of the research team, this will be done by sharing secure data folders. No data will be shared by other means (e.g.: email).

Storage

Raw data will be stored on the researcher's personal laptop which is password protected and will be saved on the University of Sheffield server or MMU server. After saving the raw data will be destroyed from the recording device.

Information for WP 1,2,4,5,6 will be stored on Runswick-Cole's University of Sheffield Google. Information for WP 3 will be stored on Hatton's Manchester Metropolitan University Dropbox for Business account. Access will only be granted to members of the research team where needed.

Personal details will be stored on the secure University of Sheffield server, UniFileStore which is the accepted secure storage for personal data as per University of Sheffield guidelines and for WP 2 on Manchester Metropolitan University's secure DropBox account.

See also data management plan in Section 8.6.

6 STUDY SETTING

Research sites are the organisations with day-to-day responsibility for the locations where a research project is carried out. The majority of this study will be carried out on line (e.g.: survey, discussion groups, digital storytelling workshops) however there are two research sites for this study:

1. The University of Sheffield. The University of Sheffield will host Spinning Plates group meetings and findings synthesis discussions (Phase 1 & 6).
2. Manchester Metropolitan University. Manchester Metropolitan University will host survey design workshops (Phase 3).

Both organisations are able to provide accessible, safe and welcoming environments for participants with access to transport links.

Phase	Activity	Venue
1. Spinning Plates group	hybrid discussion groups including 5 face-to-face meetings	The University of Sheffield and Manchester Metropolitan University
2. Lit Review	NA	NA
3. Survey design	survey design workshops x 2	Manchester Metropolitan University
4. Online interviews	interviews x 24	Online
5. Online digital storytelling workshops	2 x workshops	Online
6. Findings synthesis	part of Spinning Plates group discussions	The University of Sheffield and Manchester Metropolitan University

7 SAMPLE AND RECRUITMENT

7.1 Eligibility Criteria

Participants in this study fall into two groups

1. Carers of adults with learning disabilities.

For the purposes of this study, an adult with learning disabilities is understood as a person, over the age of 18, who may have difficulties in understanding new or complex information, learning new skills and/or coping independently (NHS, 2018). A carer is defined as anyone aged over 18 years, living in any setting, who provides unpaid care, help, or support to an adult with learning disabilities with care needs whether for a few hours, days, or weeks. We understand care to include: ‘hands on’ personal care and/or emotional support, managing appointments, dealing with medications; and support with day-to-day tasks including: socialising, shopping and household management. Crucially, we will also include participants who are caring ‘remotely’, that is, they may not deliver ‘hands-on’ care day-to-day but have caring responsibilities which they carry out from a distance.

2. People with learning disabilities

For the purposes of this study, an adult with learning disabilities is understood as a person, over the age of 18, who may have difficulties in understanding new or complex information, learning new skills and/or coping independently (NHS, 2018).

The inclusion of participants with learning disabilities in the “Spinning Plates Group” will ensure that the experiences of people with learning disabilities are centred in the study, alongside those of their carers.

The focus of the study is on carers of adults with learning disabilities, carers of children under the age of 18 will not be included, nor will carers of disabled adults who do not identify as having learning disabilities.

7.1.1 Inclusion criteria

Group One: Carers of adults with learning disabilities

To participate in this study, a person must:

- currently be a carer of an adult with learning disabilities (over 18)
- or have cared for an adult with learning disabilities over the last five years
- live in the UK.

Group Two: People with learning disabilities

To participate in this study, a person must

- identify as having a learning disability
- be over the age of 18
- live in the UK.

We recognise the intersectional impacts of race, class, gender, disability and sexuality in carers’ lives and will seek to recruit participants from diverse backgrounds through the research team’s extensive networks and will work with individuals and with communities to remove the barriers to their participation.

7.1.2 Exclusion criteria

Carers of children with learning disabilities will be excluded from the study.

Carers and people with learning disabilities living outside the UK will be excluded from the study.

Carers of people who do not identify as having learning disabilities are excluded from the study

Disable people who do not identify as having learning disabilities are excluded from the study.

7.2 Sampling

Our sampling methods fit within a qualitative research paradigm. We have chosen the number of participants in order to generate a rich data set that will allow us to reach saturation.

7.2.1 Size of sample

Phase One - Spinning Plates Group (Sample = 6 carers and 3 people with learning disabilities)

This sample size will allow for small group discussion, co-authoring of a research journal while at the same time ensuring that there are enough group members to share the work of the group across an extended period of time.

Phase Three - Survey Design Workshops: (Sample = 6 carers of people with learning disabilities)

The small group will work together to co-produce a survey about parent mental health. Working with the WP lead, Hatton, the PDRA and Lead and Joint Applicants, this group size will facilitate rich discussion.

Phase Three - Survey participants (Sample = 300 carers of adults with learning disabilities)

Through our experience of survey-based research, we expect 300 participants to be a realistic target for the study and that this will allow us to generate rich insights from the survey. This is an approach that we have used before in the UKRI/NIHR Coronavirus and People with Learning Disabilities Study.

Phase Four - Qualitative Interviews: (Sample = 24* participants)

A recent systematic review into data saturation for sample size found all 23 studies included reached saturation in under 25 interviews (Hennink and Kaiser, 2021)

Phase Five - Digital storytelling workshops: (Sample = 24* participants)

Based on our previous research, we have found that workshops with 12 participants work well. We will hold two workshops with 12 participants in each.

Phase Five - Viewing workshops: (Sample = 24* participants)

Phases Four and Five are interconnected phases. In Phase Four 24 participants will take place in narrative interviews before taking part in the digital storytelling workshops in Phase Five. A recent systematic review into data saturation for sample size found all 23 studies included reached saturation in under 25 interviews (Hennink and Kaiser, 2021).

Participants will be invited to participate in one of two events to view the digital stories. This approach to sampling will allow us to generate 24 short films (digital stories) to address the questions of how carers' conceptualise and experience mental health and support.

Phase Six - Findings Synthesis: (Sample = 6 carers and 3 people with learning disabilities)

Participants in this phase are the same participants as in Phase One, that is, they are members of the Spinning Plates Group who will take part in the findings synthesis as part of the Spinning Plates Groups activities.

7.2.2 Sampling technique

In Phase 4 we will use a combination of convenience, snowballing and purposive sampling. A sample grid will identify the key characteristics we would like included in our sample including age, gender, ethnicity, socio-economic status, sexuality, geographical location and family living arrangements. People will self-refer to the project via the dissemination of the project information. Once the initial 10-12 participants have been recruited, we will purposively recruit people with the outstanding characteristics on the sample grid.

Recruitment will be conducted using multiple routes:

1. Through members of the research team’s networks as ‘trusted’ members of those communities, including carer organisations and self-advocacy organisations, who work with diverse communities
2. social media networks (the Research Leadership Team has a combined Twitter following of 33K+
3. family carers who have consented to be contacted about other projects through the UKRI/NIHR Coronavirus and People with Learning Disabilities Study, family carer organisations and networks
4. Via selected local authorities with higher proportions of people from minority ethnic communities to attempt to ensure diversity within the survey sample.

We recognise that this multi-point recruitment strategy is to a certain extent using convenience and snowball sampling - in the absence of comprehensive databases we have found these are the most effective strategies for recruiting family carers available to us.

7.3 Recruitment

As detailed in 7.3.1 below, a sample grid will be used to ensure diversity in the sample. People will self-refer using the study documentation circulated via various routes. Potential participants will contact a member of the research team by email or telephone.

The PDRA will contact the participant via email or phone to establish that the person is eligible to take part in the study and arrange to send the information sheet. A week later, the PDRA will contact the participant to answer any questions the person may have and to see if they would like to take part. A convenient time for the interview will be arranged.

7.3.1 Sample identification

We will record the following characteristics for each group of participants.

Group One: carers of adults with learning disabilities

Participant Number	Age	Gender	Ethnicity	Sexuality	Geographical location (urban/rural)	Age of the adult with learning disabilities they care for	Are they living with the person they care for? Yes/No

Group Two: adults with learning disabilities

Participant Number	Age	Gender	Ethnicity	Sexuality	Geographical location (urban/rural)	Age of the person/s who care for them	Are they living with the person/s who care for them? Yes/No

We will then purposively sample across the potential participants to ensure diverse representation, working with the co-applicants to draw on their networks to diversify the sample further where necessary.

Participant identification

All members of the research team (KRC; SR;CH;PD; EC;CK; PDRA) will all be involved in the identification and recruitment of participants.

Methods

- Information will be disseminated online and via the research team's networks, including carers' organisations and self-advocacy groups. The research team will draw on their diverse networks to support recruitment. Potential participants will be able to talk to the member of the team leading the strand and to the Lead/Joint Lead applicant should they wish.
- Study adverts will be made available in easy read versions and as a short film. This will be shared on social media and via carers' organisations and organisations of people with learning disabilities.

Sources of information to identify the participants

We will ask participants to self-identify as either carers of adults with learning disabilities (participant group 1) or as a person with learning disabilities (participant group 2).

The only information we will collect about the participants is:

Group One: age; gender; sexuality; geographical location (urban/rural); age of the cared for person; do they live with the person they care for

Group Two: age; gender; sexuality; geographical location (urban/rural); age of the person/s who care for them; do they live with the person/s who care for them?

Payment

Participants will be remunerated for their time and expertise.

In Phase 1, we are seeking to remunerate 9 participants in the 'spinning plates' group with vouchers for their participation in 13 meetings lasting two hours at the Involve rate of £25 per hour (3x13x2x25= £3900).

In Phase 3 we are seeking vouchers to remunerate 6 participants participation in 2 workshops lasting 2 hours at Involve rates of £25 per hour (6x2x5x25 = £1500)

In Phase 4, we are seeking to remunerate 24 participants for taking part in one interview @ £30 per interview (24x30= £720)

In phase 5, we are going to remunerate 24 participants for 5 hours of participation in digital storytelling workshops at the Involve rates of £25 per hour (24x5x25= £3,000)
In addition, we seek vouchers to remunerate participation in two film viewing events with 12 participants at each, lasting two hours (2x12x2x25= £1200

Phase 6 will be part of the Spinning Plates group meetings as detailed above.

We seek £750 to remunerate PPI members of the steering group and £450 to meet access costs.

7.3.2 Consent

An information sheet will be given to all participants. Easy-read versions and versions in community languages will be available where relevant and we will adapt the research information to make sure it is in a form that meets participants' communication styles. Any adapted material will at a minimum include information contained in the easy read information sheets. These will make clear the purpose of the research, what it will involve and the benefits, risks, and burdens of participation for each individual. It will be clearly stated that participation is voluntary and that it will be possible for participants to withdraw at any time. Participants will be encouraged to keep the information sheet for reference. The information sheet and consent form (easy read version available where relevant) will be reviewed with each participant at the first contact and at the subsequent research activities. Verbal consent forms will be used for remote interviews/workshops.

We take the view that consent is a process that must be earned over time. We will take heed from a project on participation, copyright, and informed consent, in which the authors argued in relation to people accessioning material to museums: ‘Discuss future use. Discuss possible contexts. Discuss who will keep in touch with who and make sure there’s a point of ‘closure’ in the project where all this is discussed’ (Graham et al, 2012: 3). We feel these are very useful recommendations for our project also.

8 ETHICAL AND REGULATORY CONSIDERATIONS

A favourable ethical opinion for the study has been granted from The University of Sheffield Ethics Committed for the planned start date of 1st October 2022. Associated covering letters, information sheets, consent forms, risk assessment and safeguarding and distress protocols have been included with the application.

There are different ethical considerations across the research design including informed consent and power. Researcher-participant power imbalances will be minimised by the researchers spending time explaining the research to participants in advance of participation. The researchers will constantly pay attention to whether people feel comfortable. Researchers will also take care to notice any distress caused by any questions and any interviewing or workshop activity. Activity will be paused/stopped in this case. For those who have communication difficulties, accessible formats will be used to interview including signs and symbols as well as photographs. Natural breaks will be taken according to whether participants become tired or just need a rest from participation. We will ensure that we provide signposts to where people might get help if questions arise from the interviews or workshops.

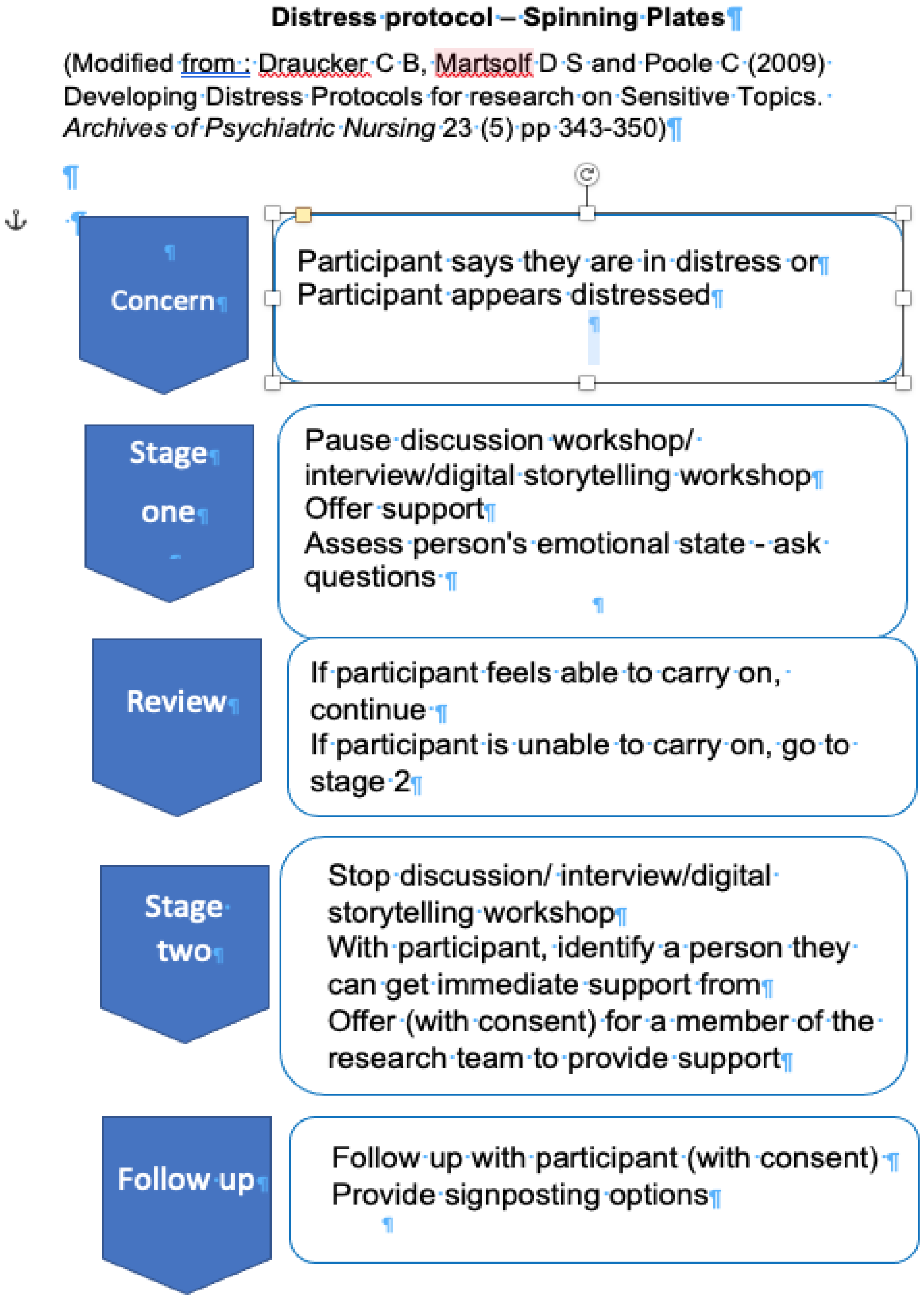
This research will be guided by the British Psychological Society Code of Human Research Ethics (2021) and will uphold the principles of:

- respect for participants;
- scientific integrity;
- social responsibility;
- maximising benefit and minimising harm.

Much of the research will take place on-line. Face-to-face and hybrid research meetings will take place either at the University of Sheffield or at Manchester Metropolitan University. We will abide by the Universities' health and safety practices to ensure that participants feel welcome and safe at meetings at the Universities. We will provide refreshments and remuneration for travel and for participants' time at these meetings.

8.1 Assessment and management of risk

There is a risk that a participant may become upset during discussion of their mental health in the discussion groups, workshops and interviews. The team is experienced in working with carers and with people with learning disabilities. In addition, they will follow the Distress Protocol that seeks to minimise personal distress on the part of the participant in relation to their involvement in research and to uphold the highest principles of ethical and safe research.The researchers will follow the distress protocol:



Distress protocol – Spinning Plates

(Modified from : Draucker C B, Martsolf D S and Poole C (2009) Developing Distress Protocols for research on Sensitive Topics. *Archives of Psychiatric Nursing* 23 (5) pp 343-350)

Concern

Participant says they are in distress or
Participant appears distressed

Stage one

Pause discussion workshop/ interview/digital storytelling workshop
Offer support
Assess person's emotional state - ask questions

Review

If participant feels able to carry on, continue
If participant is unable to carry on, go to stage 2

Stage two

Stop discussion/ interview/digital storytelling workshop
With participant, identify a person they can get immediate support from
Offer (with consent) for a member of the research team to provide support

Follow up

Follow up with participant (with consent)
Provide signposting options

Risk management

A full risk assessment has been carried out which will be reviewed regularly:

Activity being assessed:	Online interviews and workshops and face to face workshops			Reference no:
Location:	Online and rooms at The University of Sheffield and at Manchester Metropolitan University	Assessment date:	5th June, 2022	Review period:

Significant Hazards What could cause harm?	**What harm might occur, and to whom?** Remember to consider all affected groups	**Existing control measures**	**Risk Rating (with current controls)**			**Additional control measures** What can we do / use / put in place to further reduce the risks to an acceptable level?	**Residual Risk**		
			L	**S**	**RR**		**L**	**S**	**RR**

Researchers, poor workstation set up	researchers Poor workstation setup can harm health	All members of the research team work in organisations that have conducted workstation assessments and where further equipment and modifications are available as required on health and safety grounds	**3**	**2**	**low**	Lead applicant will check team have had DSE assessment	**2**	**1**	**low**
Isolation and uncertainty	Members of the research team	Regular weekly meetings to support the PDRA, WP meetings and strategies to foster peer support	**3**	**2**	**Low**	Lead/Joint applicant to ensure meetings take place on a regular basis	**2**	**1**	**low**

Risk of COVID infection COVID lockdown / restrictions	researchers and participants	Offer a mixture of face to face, online and hybrid options depending on COVID risk levels	**3**	**3**	**Medium**	Workshops will not take place if the researchers or participants are unwell /showing signs of COVID or have had a positive lateral flow or PCR test. The researcher and participants will also be following government guidance. We have considered a number of scenarios - including national/local lockdowns and easing of social distancing - and will adhere to the latest NIHR	**2**	**3**	**M**

						and University guidance on research. Our Research Team will review risks regularly and draw in good research practice during a pandemic (e.g. Lupton, 2020). As a team we are already experienced in a mix of online and face-to-face methods in our research. Any face-to-face Co-production workshops can be moved to online workshops (with breakout rooms). COVID mitigations will be a standing item on the			

						agenda for the weekly meetings with the Joint Lead Applicant and PDRAs			

Participants disclosure of harm	Participant and indirectly family and professionals	Researchers are already accountable to safeguarding policies in their universities/services.	**3**	**3**	**Medium**	Remind participants of *the limits of confidentiality clause* in case of reporting abuse/malpractice Ensure clearly and accessible communicated in information sheets Immediately complete Incident Record Form and share with Designated Safeguarding Contact	**2**	**3**	**M**

Participant exhibits high levels of emotional distress	Participants	The research team are experienced in working with carers and with people with learning disabilities. In addition, they will follow the Distress Protocol and Safeguarding Protocol- that seeks to minimise personal distress on the part of the participant in relation to their involvement in research and to uphold the highest principles of ethical and safe research.	**2**	**2**	**low**	The researcher will offer immediate support. Assess well-being: •Tell me how you feel? •Do you feel you are able to go on about your day? •Do you feel safe? If participant feels able to carry on - resume interview/discussion If participant is unable to carry on: * Remove participant from discussion and	**2**	**2**	**L**

						accompany to quiet area or online breakout room or discontinue interview; * Encourage the participant to contact trusted adult OR * Offer, with participant consent, for a member of the research team to do so. *Follow participant up with courtesy call (if participant consents)			

Researchers working alone	Researchers	All one-to-one interviews are online so there are no issues with loan working. At face to face workshops researchers at least two researchers (PDRA and WP Lead) will be present.	**2**	**2**	**L**	Ensure two researchers present at face to face workshops	**2**	**2**	**L**
Risks to emotional wellbeing of researcher	Researcher	The project focuses on the mental health of carers of adults with learning disabilities. The research team includes applicants who are carers of adults with learning disabilities and close allies to people with learning disabilities and	**2**	**2**	**L**	Wellbeing checks will be part of every team meeting.	**2**	**2**	**L**

		their carers. There is potential for the content of the interviews to cause some distress or upset. The first point of support will be peer support from the research team, however, should a researcher become further distressed the Lead Applicant will be informed and offer support, including signposting to the wellbeing services.							

Risks to emotional wellbeing of film makers/facilitators	Facilitator/film makers	The project focuses on the mental health of carers of adults with learning disabilities. There is potential for the content of the digital workshops to cause some distress or upset to the filmmakers/facilitators. The first point of support will be peer support from the research team, however, should a researcher become further distressed the Lead Applicant will be informed and offer support, including signposting to	**2**	**2**	**L**	The film makers/facilitators are: informed of the nature of the research and the type of data. Wellbeing checks will be part of the supervision of the film makers/facilitators.	**2**	**2**	**L**

		wellbeing services.							
Risk to the emotional wellbeing of the person transcribing interviews	Individuals transcribing the interviews	There is potential for the content of the interviews to cause some distress or upset. The first point of support will be the Work Package Lead. However, should a transcriber become further distressed the Lead Applicant will be informed and offer support,	**2**	**2**	**L**	The person transcribing is : informed of the nature of the research and the type of data; is alerted in advance of transcription to any potentially ‘challenging’ interviews and has de-briefing sessions with the Lead Applicant or Work Package	**2**	**2**	**L**

		including signposting to wellbeing services.				Lead of the research team			

Action number	Action required	Who is responsible?	By when?	Date completed
1.	Follow COVID guidance	Lead Applicant Runsiwick-Cole/ Joint Lead Applicant Ryan	Immediate and ongoing	June, 2022
2.	Researcher to inform participants that will be advised to cancel should they become symptomatic and have to self isolate due to coming into contact with someone who has tested positive for COVID-19	Lead Applicant Runsiwick-Cole/ Joint Lead Applicant Ryan	Immediate and ongoing	June, 2022

4.	Research team will monitor COVID rates and pivot to online workshops if necessary	Lead Applicant Runsiwick-Cole/ Joint Lead Applicant Ryan	Immediate and ongoing	June, 2022
6.	Ensure the research area aware of and engage with to the Distress Protocol and Safeguarding Protocol and that The Executive Team regularly reviews this risk assessment and the Distress Protocol and Safeguarding Protocol	Lead Applicant Runsiwick-Cole/ Joint Lead Applicant Ryan	Immediate and ongoing	June, 2022
7	Ensure regular debriefing meetings between researchers team to discuss emotive nature of the research	Lead Applicant Runsiwick-Cole/ Joint Lead Applicant Ryan	Immediate and ongoing	June, 2022

Likelihood	Guide Description
5	Very likely/imminent – certain to happen
4	Probable – a strong possibility of it happening
3	Possible – it may have happened before

Severity	Guide Description
5	Catastrophic - fatality, catastrophic damage
4	Major – significant injury or property damage, hospitalisation
3	Moderate - injury requiring further treatment, lost time

2	Unlikely - could happen but unusual	2	Minor - first aid injury, no lost time
1	Rare – highly unlikely to occur	1	Very minor – insignificant injury

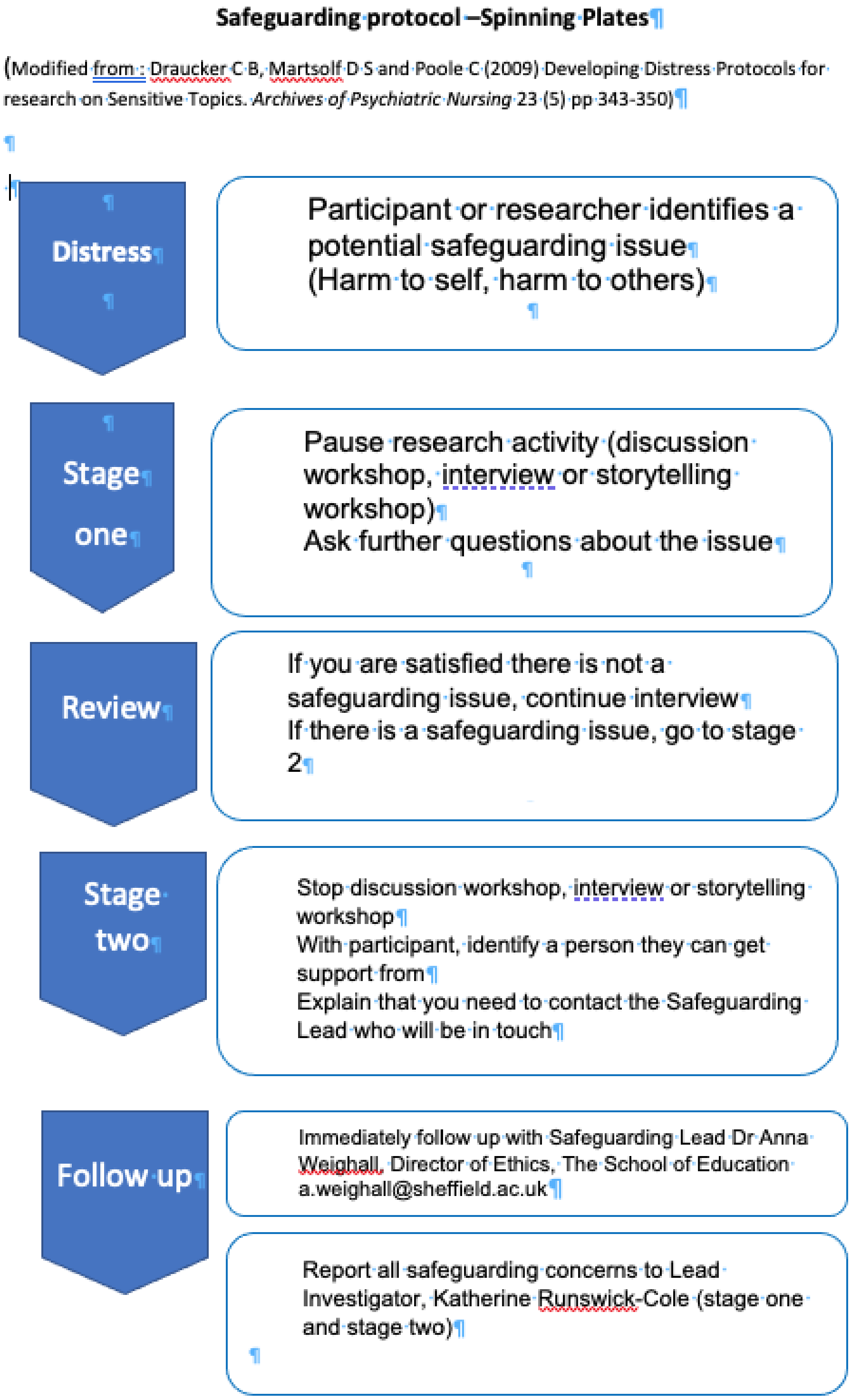
		Severity (S)				
		1	**2**	**3**	**4**	**5**
Likelihood (L)	**5**	5	10	15	20	25
	4	4	8	12	16	20
	3	3	6	9	12	15
	2	2	4	6	8	10
	1	1	2	3	4	5

Risk Rating (RR)	**Action**
High Risk	Stop the task/activity until controls can be put into place to reduce the risk to an acceptable level
Medium Risk	Determine if further safety precautions are required to reduce risk to as low as is reasonably practicable
Low Risk	No further action, keep under review

Signature of Risk Assessor		Name / job title:	Katherine Runswick-Cole Professor of Education
Details of any persons consulted	Beth Mann - Deputy DHSO, School of Education		

Safeguarding

If the researchers observe or are told about anything that they may be concerned about, they will follow the safeguarding protocol and immediately raise their concern with the lead investigator, Katherine Runswick-Cole. Where necessary, the Study Steering Committee will be consulted to seek guidance on how to proceed. If the information is deemed to warrant further action, then we will escalate to the safeguarding lead for the project: Dr Anna Weighall, Director of Ethics, The School of Education, The University of Sheffield. The project documentation will make it clear to participants (and to those that opt out of participation) that while the researchers will maintain their duty of research confidentiality to participants as far as possible, that if participants reveal that they or someone else is at risk of harm, we will need to pass this on to the University's safeguarding lead. We will discuss this with the participant.



Safeguarding protocol –Spinning Plates

(Modified from : Draucker C B, Martsolf D S and Poole C (2009) Developing Distress Protocols for research on Sensitive Topics. *Archives of Psychiatric Nursing* 23 (5) pp 343-350)

Distress

Participant or researcher identifies a potential safeguarding issue
(Harm to self, harm to others)

Stage one

Pause research activity (discussion workshop, interview or storytelling workshop)
Ask further questions about the issue

Review

If you are satisfied there is not a safeguarding issue, continue interview
If there is a safeguarding issue, go to stage 2

Stage two

Stop discussion workshop, interview or storytelling workshop
With participant, identify a person they can get support from
Explain that you need to contact the Safeguarding Lead who will be in touch

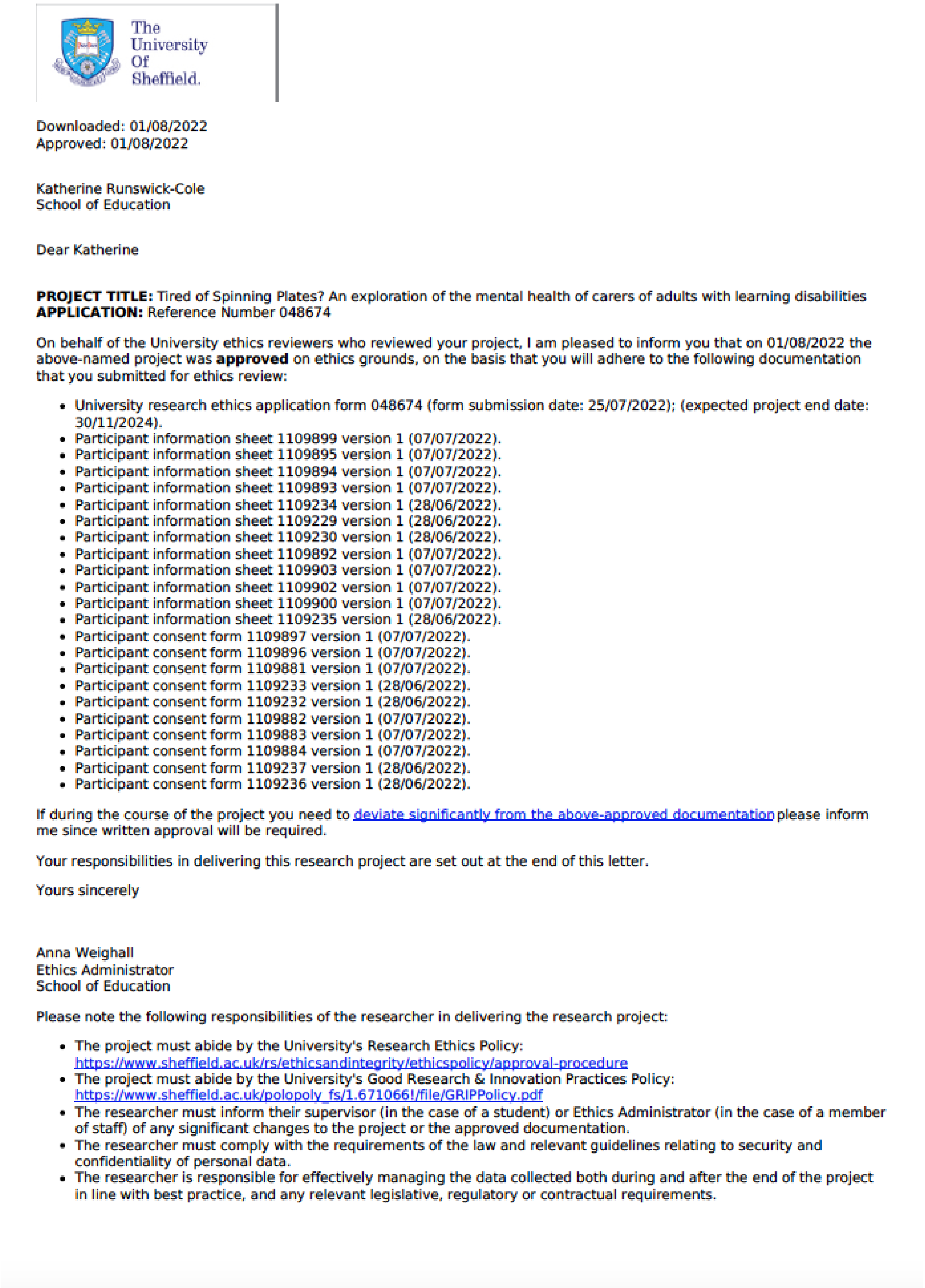
Follow up

Immediately follow up with Safeguarding Lead Dr Anna Weighall, Director of Ethics, The School of Education a.weighall@sheffield.ac.uk

Report all safeguarding concerns to Lead Investigator, Katherine Runswick-Cole (stage one and stage two)

S

8.2 Research Ethics Committee (REC) and other Regulatory review & reports We have received ethical approval through the University of Sheffield's ethics



The
University
Of
Sheffield.

Downloaded: 01/08/2022
Approved: 01/08/2022

Katherine Runswick-Cole
School of Education

Dear Katherine

PROJECT TITLE: Tired of Spinning Plates? An exploration of the mental health of carers of adults with learning disabilities
APPLICATION: Reference Number 048674

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 01/08/2022 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 048674 (form submission date: 25/07/2022); (expected project end date: 30/11/2024).
- Participant information sheet 1109899 version 1 (07/07/2022).
- Participant information sheet 1109895 version 1 (07/07/2022).
- Participant information sheet 1109894 version 1 (07/07/2022).
- Participant information sheet 1109893 version 1 (07/07/2022).
- Participant information sheet 1109234 version 1 (28/06/2022).
- Participant information sheet 1109229 version 1 (28/06/2022).
- Participant information sheet 1109230 version 1 (28/06/2022).
- Participant information sheet 1109892 version 1 (07/07/2022).
- Participant information sheet 1109903 version 1 (07/07/2022).
- Participant information sheet 1109902 version 1 (07/07/2022).
- Participant information sheet 1109900 version 1 (07/07/2022).
- Participant information sheet 1109235 version 1 (28/06/2022).
- Participant consent form 1109897 version 1 (07/07/2022).
- Participant consent form 1109896 version 1 (07/07/2022).
- Participant consent form 1109881 version 1 (07/07/2022).
- Participant consent form 1109233 version 1 (28/06/2022).
- Participant consent form 1109232 version 1 (28/06/2022).
- Participant consent form 1109882 version 1 (07/07/2022).
- Participant consent form 1109883 version 1 (07/07/2022).
- Participant consent form 1109884 version 1 (07/07/2022).
- Participant consent form 1109237 version 1 (28/06/2022).
- Participant consent form 1109236 version 1 (28/06/2022).

If during the course of the project you need to deviate significantly from the above-approved documentation please inform me since written approval will be required.

Your responsibilities in delivering this research project are set out at the end of this letter.

Yours sincerely

Anna Weighall
Ethics Administrator
School of Education

Please note the following responsibilities of the researcher in delivering the research project:

- The project must abide by the University's Research Ethics Policy: https://www.sheffield.ac.uk/rs/ethicsandintegrity/ethicspolicy/approval-procedure
- The project must abide by the University's Good Research & Innovation Practices Policy: https://www.sheffield.ac.uk/polopoly_fs/1.671066!/file/GRIPPolicy.pdf
- The researcher must inform their supervisor (in the case of a student) or Ethics Administrator (in the case of a member of staff) of any significant changes to the project or the approved documentation.
- The researcher must comply with the requirements of the law and relevant guidelines relating to security and confidentiality of personal data.
- The researcher is responsible for effectively managing the data collected both during and after the end of the project in line with best practice, and any relevant legislative, regulatory or contractual requirements.

Documentation includes

- information sheets and consent forms;
- short film advertising the study;
- distress protocol;
- safeguarding protocol;
- risk assessment
- confidentiality agreements for
  - transcribers
  - film makers/ facilitators
  - support workers
- film release form
  - for participants
  - for those identifiable in the film

Regulatory Review & Compliance

No patients are included in this study.

Amendments

If amendments are required, the Lead Applicant will submit an amendment to the University of Sheffield Ethics Committee via a form outlining the details of proposed amendments along with any ethical considerations. Any new/amended supporting documents will be uploaded (with changes marked in track changes. An appropriate reviewer will be appointed, this is usually the lead reviewer from the original application. If the lead reviewer is no longer available, an appropriate alternative will be identified.

8.3 Peer review

The National Institute Health Research (NIHR) Health Service Design Research Funding Committee provide the following standard for peer review for studies:

High quality peer review

Peer review is independent, expert, and proportionate:

a) **Independent**: At least two individual experts have reviewed the study. The definition of independent used here is that the reviewers must be external to the investigators' host institution and not involved in the study in any way.

b) **Expert**: Reviewers have knowledge of the relevant discipline to assess the methodological qualitative aspects of the study.

c) **Proportionate**: Peer review is commensurate with the size and complexity of the study.

8.4 Patient & Public Involvement

We have described how the idea for this research emerged and the PPI involvement in the development of the application above.

Our approach is to embed PPI in every phase of the research to the extent that it is not considered an adjunct to the research. To do this, we will establish the "Tea, Cake and Spinning Plates" group (Phase 1). This group of 6 carers of adults with learning disabilities and 3 adults with learning disabilities, the PDRA and Lead Applicant, and will meet bi-monthly. It will be co-chaired by Ryan, the PPI lead and by a family carer. Co-applicants will attend meetings when appropriate to seek guidance on their leadership of research phases. The purpose of this group is to act as an innovative hybrid of traditional PPI for the study. The group will provide guidance, feedback, and advice on each phase of the research and also act as participant co-researchers. This means that group discussions will form part of the project dataset as members will inevitably draw upon their own experiences of mental health across the life course as they reflect on the on-going research. A co-authored diary will be curated by the PDRA throughout the project. In Phase 2, the Spinning Plates group will support the rapid scoping review, in particular, we will draw on their knowledge of grey literature. In Phase 3, carers will attend two survey design workshops. In Phase 4, the Spinning plates group will support the design of the interview schedule and offer their insights into the development of the storytelling workshops in Phase 5. In phase 6, the Spinning Plates group will support the findings synthesis and will be involved in the development and delivery of outputs and their contributions recognised as co-authors. They will also support the dissemination of findings and resources (Phase 7).

We will be mindful not to overburden this group, bearing in mind their caring responsibilities, and pressures on their time (their own spinning plates). Participation will be structured to ensure that members can contribute in different ways, working flexibly and responsively as a supportive team. We appreciate the fluctuating demands on carers time so we will offer different levels and modes of involvement, from emails to phone calls, video chats and in person meetings. £3600 has been costed in to ensure the group members are remunerated for their time, and additional funds have been sought for travel and subsistence and to meet access requirements.

We will evaluate PPI involvement by briefly asking for feedback by email, phone and/or video chat. In addition, we will create a short PPI contributor survey that can be completed anonymously at the end of each research phase and/or at the end of the project. PPI involvement will be a standing item on project management meetings.

8.5 Protocol compliance

Accidental protocol deviations can happen at any time. They will be adequately documented on the relevant forms and reported to the Lead Investigator immediately.

Deviations from the protocol which are found to frequently recur are not acceptable, will require immediate action and could potentially be classified as a serious breach.

8.6 Data protection and patient confidentiality

Data management plan

- **Existing data and the need for new data**

There is limited empirical data that focuses on the mental health of carers of adults with learning disabilities. To address the research questions, the project will generate new empirical data (qualitative and quantitative). The following forms of primary data will be collected:

- ❖ Audio recordings and diary entries of the Spinning Plates group meetings, who are occupying the dual role of participants and co-researchers, as carers of people with learning disabilities, people with learning disabilities and researchers (Phase 1)
- ❖ Literature Review of existing literature (Phase 2)

- Audio recordings and research notes of discussions in survey co-design workshops (Phase 3)
- Largely quantitative survey data from family carers concerning mental health and factors potentially associated with mental health (Phase 3)
- Audio recordings and transcripts of interview data (Phase 4)
- Digital stories (short films 3-5 minutes) (Phase 5)
- Audio recordings and research notes of discussion in findings synthesis workshops (Phase 6)

- **New data**

WP1: *Spinning Plates Meetings:* bi-monthly meetings of a group of 6 carers and 3 people with learning disabilities will take place across the 26-month project (13 meetings). Data generated from these meetings will include: audio recordings; research notes and co-authored diary entries.

WP 3: *Survey Design Workshops:* Two workshops will be held at Manchester Metropolitan University with the option to attend online in hybrid format. The workshops will be used to co-produce and test survey questions which once completed will be made freely available for use by others, and understand aspects of family carer mental health, medication and support which are largely absent in the existing research literature. Data generated from these workshops will include audio recordings and research notes as well as survey questions.

WP 3: *Survey:* The survey will be administered online using the Qualtrics platform, with different language versions available and an option to go through the survey in a remote interview format. Survey data will be collected using the Qualtrics online survey software. Qualtrics provides powerful analysis features, detailed visual representations of statistical data and is easy to share across a range of platforms. We will recruit up to 300 participants to the survey using multiple routes, including social media networks.

WP 4: *Interviews:* The interviews will take place online (Total 24) using the online platform Zoom through the University of Sheffield's account. Data generated will include 24 interview transcripts.

Interviews will be transcribed using a naturalised method by a professional transcription company, which is bound by an official code of confidentiality. Each transcript will have a unique identifier and there will be a consistent layout for each transcript throughout the research project. Each transcript will include a cover sheet with interview details (date, time, place, interviewer name). Speaker tags will be used to clearly indicate the question/ answer sequence and line breaks will be used in-between turn takes. Lines and pages will be numbered for ease of finding information and pseudonyms will be used. The same pseudonyms will be used throughout the duration of the project including in published outputs and follow-up research. Transcripts will be cleaned to remove any identifying details or personal reference to other people.

WP 5: *Digital Stories:* 24 short films (2-5 minutes); transcripts of the films including elements of audio description. Digital storytelling workshops will be held online via the University of Sheffield Zoom account

WP 6: *Findings synthesis:* working with the Spinning Plates group (above) we will draw together key findings and develop teaching and learning resources for GPs, allied health professionals, social workers, support providers, and voluntary organisations, including carer-led organisations and self-advocacy groups of people with learning disabilities. In addition, we will produce tailored learning and teaching materials for mental health teams and commissioners. Data will include audio recordings of the discussions and research notes.

- **Difficulties in data sharing and measures taken to overcome these**

There is a need to share data across the research team given that the project spans more than one institution and operates collaboratively across the research team and WPs.

For the data for which The University of Sheffield is Data Controller (WP1; 2; 4 & 5; 6), the Google Suite is the University of Sheffield's preferred storage solution and will be able to meet the needs of our project. Discussions with IT colleagues within the university highlight that Google Drive can be configured to allow access to specific folders for named individuals both within and beyond the university. A project folder will be created on Google Drive and access will be granted only to the core research team who require that access for the purposes of the project: Runswick-Cole; Ryan; Hatton; Croot; Douglas; Kassa; Cisneros and the PDRA. Technical/artist facilitators supporting the digital storytelling workshop will have limited access to the folders containing videos for post-production. The transcriber will also have limited access to files for transcription. Facilitators and transcribers will be asked to sign a confidentiality agreement.

Manchester Metropolitan University is the data controller for WP 3. Manchester Metropolitan University's secure Dropbox for Business is the preferred storage solution and will meet the needs of the project. Drop Box can also be configured to allow access to the core research team for research purposes.

Where any data needs to be transferred between members of the research team this will be done by sharing secure folders. No data will be transferred by other means (e.g.: email, physical transfer)

- **Backup and security of data**

Firstly, we propose to use a dedicated University of Sheffield Google Drive folder for the project to store and share any data (in WP 1;2; 4;5;6) that is low risk, by which we mean any data that are (i) not sensitive data AND (ii) not personal data AND (iii) not of high intellectual property value. All three conditions must be met for the data to be shared on the Google Drive area. This approach is in line with advice from the UK Data Service which states that: "Cloud data storage should be avoided for high-risk information such as files that contain personal or sensitive information, or information that has a very high intellectual property value."[1]. The Google Drive project folders will have access enabled only to members of the research team and, furthermore, the different folders within that main project Google Drive folder will operate on a minimal 'need to access' basis with access shared to as few members of the research team as possible.

Secondly, any data that are (i) highly sensitive OR (ii) personal data OR (iii) of high intellectual property value will **not** be placed on Google Drive. To be explicit, if any one condition is met then the data will not be placed on the project Google Drive area. No personal data will be processed outside of the UK. Such data will be stored on the University of Sheffield's institutional secure networked environment and corporate storage platforms of the research team member who collected the data and all will comply with appropriate security standards, including ISO 27001. No such data will be stored on any local drives (e.g., computers, USB flash drives). Security, processing, and data protection in all institutions will be compliant with the GDPR and minimise exposure to risk.

For WP 3, Manchester Metropolitan University will follow the same procedures on Dropbox for Business, ensuring that personal data is stored in the University's secure networked environment.

Digital stories will be stored on The University of Sheffield's google drive and in the University's secure Kaltura account with permissions granted as appropriate.

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[1] https://dam.ukdataservice.ac.uk/media/605073/2018-01-12_data_management_basics_final_-pdf.pdf

Consent forms will be scanned, encrypted, and stored in a separate password-protected folder to the research data files. Tangible artefacts (photograph) will be scanned and stored digitally in password protected folders. Hard copies of the photographs will be stored in a locked cabinet. Interview transcripts will be anonymised and all identifying details will be redacted prior to analysis.

The PDRA will be supported by the Lead Applicant/Joint Lead Applicant in the importance of data management and storage, to ensure all files are correctly stored in password protected files on university computers and any field notes are converted to a digital format and hard copies are carefully stored in a locked cabinet.

- **Deletion**

All project-related raw data files will be deleted 48 months after the project's funding end date. This allows sufficient time for the research team to complete further analyses and produce necessary academic and non-academic outputs. With permission, we will store participants' contact details for 24 months after the project so that we can contact them about future research.

The films will be published on the project website, healthtalk.org and socialcaretalk.org and on restoryingautism.com. To ensure the participants retain the right to be forgotten, participants will be able to contact the Lead Applicant to ask them to delete their digital stories from one or all these websites.

- **Copyright and intellectual property ownership of the data**

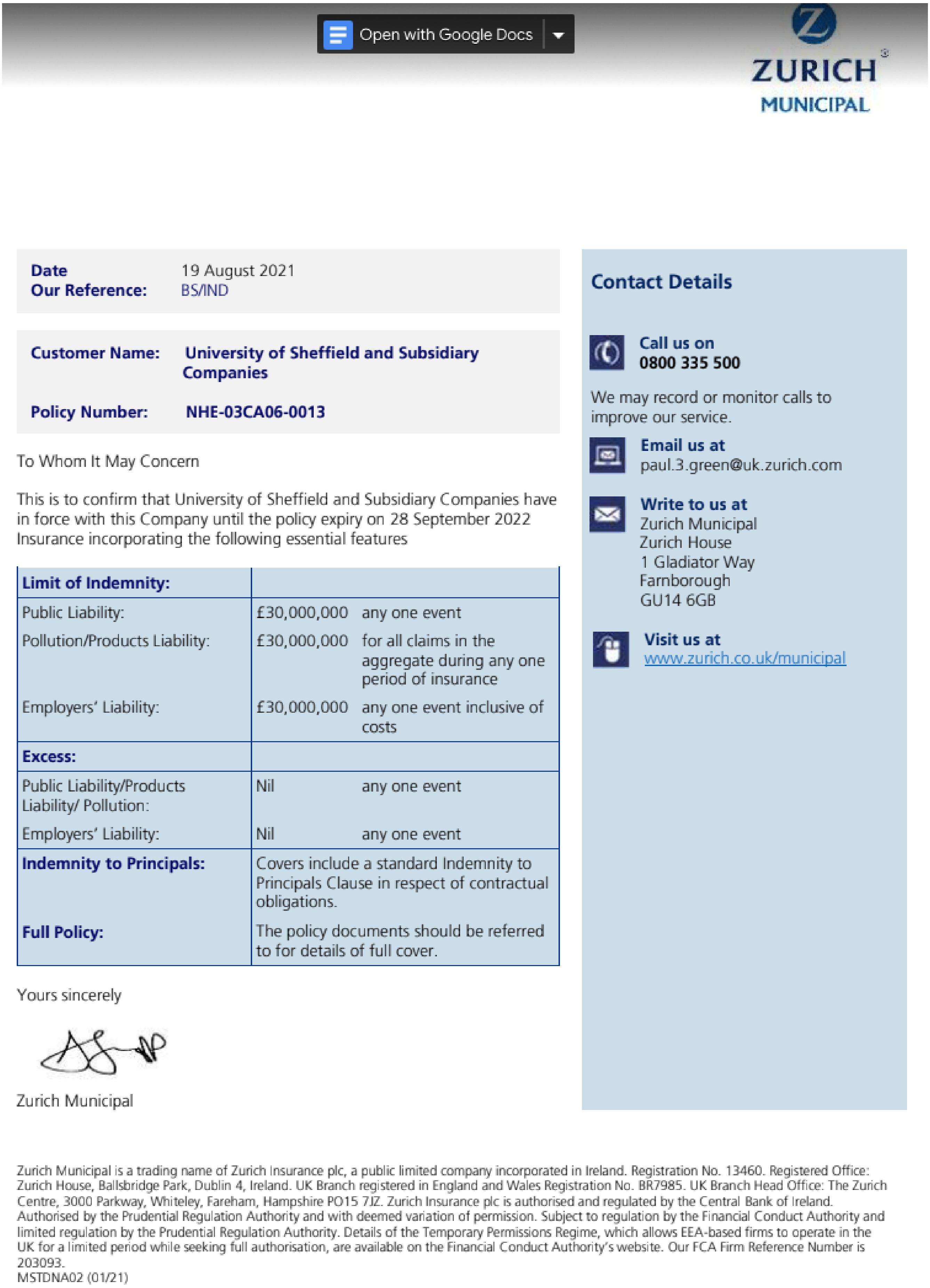
The copyright of the data will be held institutionally by the University of Sheffield for WPs 1,2 4, 5,6, and by Manchester Metropolitan University for WP 3.

- **Responsibilities**

The Lead Applicant will be responsible for implementing this data management plan for the University of Sheffield. The Joint Lead Applicant will be responsible for implementing the data management plan in relation to WP 3 with support from the PDRA regarding specific aspects of the research as indicated above. The PDRA will undertake training provided by the University of Sheffield and Manchester Metropolitan University on Research Data Management.

8.7 Indemnity

The University of Sheffield has in place insurance against liabilities for which it may be legally liable and this cover includes any such liabilities arising out of the above research project/study



ZURICH
MUNICIPAL

Date 19 August 2021
Our Reference: BS/IND

Customer Name: **University of Sheffield and Subsidiary Companies**

Policy Number: **NHE-03CA06-0013**

To Whom It May Concern

This is to confirm that University of Sheffield and Subsidiary Companies have in force with this Company until the policy expiry on 28 September 2022 Insurance incorporating the following essential features

Limit of Indemnity:		
Public Liability:	£30,000,000	any one event
Pollution/Products Liability:	£30,000,000	for all claims in the aggregate during any one period of insurance
Employers' Liability:	£30,000,000	any one event inclusive of costs
Excess:		
Public Liability/Products Liability/ Pollution:	Nil	any one event
Employers' Liability:	Nil	any one event
Indemnity to Principals:	Covers include a standard Indemnity to Principals Clause in respect of contractual obligations.	
Full Policy:	The policy documents should be referred to for details of full cover.	

Yours sincerely

Zurich Municipal

Contact Details

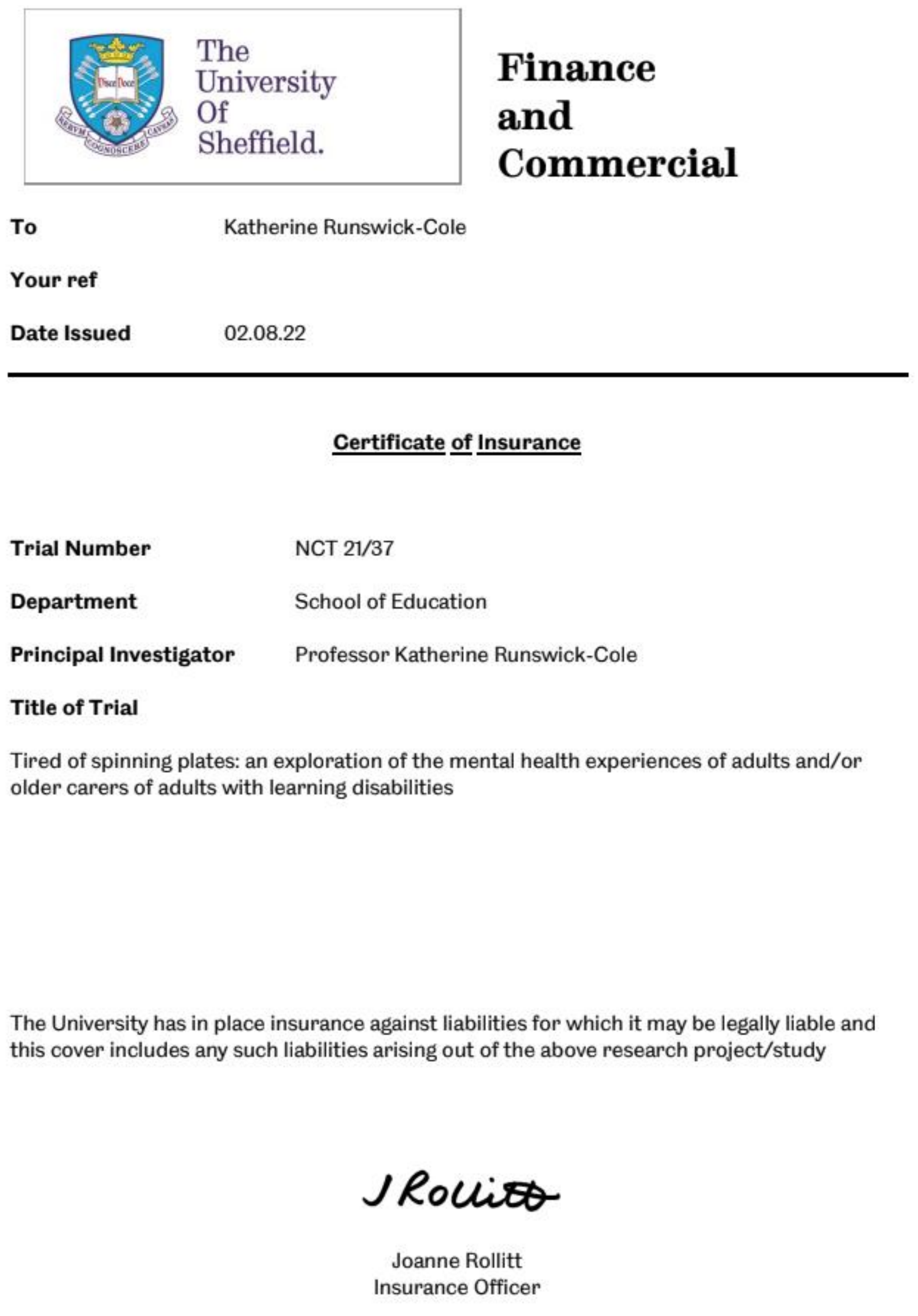
Call us on
0800 335 500

We may record or monitor calls to improve our service.

Email us at
paul.3.green@uk.zurich.com

Write to us at
Zurich Municipal
Zurich House
1 Gladiator Way
Farnborough
GU14 6GB

Visit us at
www.zurich.co.uk/municipal



The University Of Sheffield.

Finance and Commercial

To	Katherine Runswick-Cole
Your ref	
Date Issued	02.08.22

Certificate of Insurance

Trial Number	NCT 21/37
Department	School of Education
Principal Investigator	Professor Katherine Runswick-Cole

Title of Trial

Tired of spinning plates: an exploration of the mental health experiences of adults and/or older carers of adults with learning disabilities

The University has in place insurance against liabilities for which it may be legally liable and this cover includes any such liabilities arising out of the above research project/study

J Rollitt

Joanne Rollitt
Insurance Officer

8.8 Access to the final study dataset

This project is funded by the National Institute for Health and Social Care research and therefore we will comply with their commitment to Open Data. The NIHR strongly supports the sharing of data in the most appropriate way, to help deliver research that maximises benefits to patients and the wider public, the health and care system. For WPs 1,2,4,5,6 Runswick-Cole will be responsible for preparing the data in line with our Data Management Plan and uploading the data to (ii) ORDA (the open data repository for the University of Sheffield. For WP3, Hatton will be responsible for preparing the data for E-Space (the open data repository for Manchester Metropolitan University).

OPEN DATA PLAN

We are committed to Open Access of research data/outputs. We will follow The NIHR's Open Research Policy (NIHR, 2022) which is underpinned by four principles:

1. Principle 1 - Articles must be immediately, freely, and openly accessible to all
2. Principle 2 - There should be no barriers to the re-use and dissemination of NIHR funded articles
3. Principle 3 - Articles must be freely discoverable
4. Principle 4 - NIHR will pay reasonable fees to enable immediate open access (NIHR, 2022)

Our data management will comply with the policies of the participating institutions. Prior to making our data open access, following the Data Protection Act 1998, data will be retained in a secure location and by secure means.

The data and online resources

Qualitative data will include:

Phase One: discussion notes, audio/video recordings and diary entries;

Phase Two: rapid literature review

Phase Three:

a. survey workshops - audio/vido recordings and discussion notes
b. survey data - 300 survey responses

Phase four: 24 narrative interview audio/video recordings and transcripts

Phase five: 24 digital stories (short films)

Phase Six: discussion notes and audio/video recordings and learning and teaching materials (using a variety of formats, including films, podcasts, images, easy read and community languages.

All will be of interest to carers, disabled people, health and social care professionals, policy makers and members of the public.

When you intend to share your data and online resources

Participants will be informed of data sharing commitments via a consent form. Digital stories (short films) will not be shared without an additional level of consent via a film release form signed by the film maker. If people who are not participants are identifiable in the films, they will also be asked to sign a release form before the film is shared. Data will be made available at the point when judged to be of value to potential users and publicised on: our project website; healthtalk.org; socialcaretalk.org and restoryingautism.com.

Where your data and online resources will be made available

For WP 1, 2,4, 5, 6 qualitative data will be made openly available ORDA (University of Sheffield).

For WP 3, qualitative data and survey data will be made openly available through E-Space (Manchester Metropolitan University).

How your data and online resources will be accessible to others

Datasets will be described/catalogued on ORDA/E-Space and publicised via the project Twitter handle/website.

Limits to data and online resources sharing

Research participants and contributors to online resources have the right to withdraw their data/contributions. Online resources; no images, audio or films will be used without consent.

Preserving datasets and online resources

Data storage in a well-known and widely used repository like ORDA/E-Space will ensure that the data produced throughout the project will be preserved/of utility to the research community long after the project has concluded. We will work collaboratively across our universities to find best ways to share/preserve our research data. Online resources will be preserved for ten years by ensuring that web address is paid and sustained 10 years after the project has finished. The resource will remain on the project website healthtalk.org; socialcaretalk.org and restoryingautism.com for as long as the platforms are live

9 DISSEMINATION POLICY

9.1 Dissemination policy

Anticipated foreground IP includes: 1) A co-authored digital diary reflecting on the research design and process hosted on the project blog. IP to vest with The University of Sheffield 2) A co-designed questionnaire including existing standardised measures to allow for comparisons with other research, bespoke questions to address important issues, and a small number of open-ended questions, hosted on the project blog. IP to vest with Manchester Metropolitan University. 3) 24 films from Phase 5 to be published on the project webpage, Socialcaretalk.org and Healthtalk.org and on restoryingautism.com. IP to vest with The University of Sheffield. 4) from Phase 6, teaching and learning resources for: GPs, allied health professionals, social workers, support providers, and voluntary organisations, including carer-led organisations and self-advocacy groups of people with learning disabilities, mental health teams and commissioners. IP to vest with The University of Sheffield. There is no background IP.

On completion of the study the data will be analysed, tabulated and the final report prepared. The final report will be made available on NIHR Open Research Website and on the project website.

Authorship of any publications by the investigators of the conclusions of the Project will be decided in accordance with usual academic practice and in consultation with the other members of the team.

In the first four months of the project, the research team will agree and sign a dissemination policy which will include

- Process for agreeing to write single, joint and multi-authored papers;
- Commitment to publish in academic, clinical and practitioner journals;
- Shared responsibility for populating the project website - housing regular news updates, blogs, project findings, digital stories

- Write learning and teaching materials focused on providing resources of carers and for people with learning disabilities and on improving professional practice and service provision in relation to the mental health of carers of adults with learning disabilities;
- Produce summary, Easy Read and community language versions of outputs
- Raise public awareness about the mental health experiences of carers of adults with learning disabilities by engaging in round table events and attending the end of project conference as well as promoting the study through their academic, professional and personal networks.
- Supporting the social media activity of the project
- Taking part in the production of short films and podcasts to promote the project.

All written and oral research outputs will acknowledge the NIHR funding in full, including the NIHR unique award identifier and include the NIHR disclaimer. We will use the following wording: “This study/project is funded by the NIHR HS&DR. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care”.

We will regularly communicate with participants about the outcome of the study in the following ways:

1. written reports and summaries following the completion of research phases. These will be made available in summary, easy read and community languages
2. blog posts on the project web pages, which will also be promoted through the project Twitter handle
3. podcasts hosted on the project website and promoted through the Twitter account.
4. short films discussing the findings hosted on the project website and promoted through the Twitter account

Participants will be able to specifically request results from the Lead Investigator once the final study report has been published.

The study protocol will be published alongside full study details on the NIHR website. The full study report will be peer reviewed and published (open access) in the NIHR Journals Library. The report will be submitted to the NIHR two weeks after the project end date and then will go through a rigorous peer review process before publication. A fully anonymised dataset will be deposited in Sheffield University’s Data depository (ORDA) for Phases 1, 2, 4,5,6 and for WP3 in Manchester Metropolitan University’s data depository (E-Space).

9.2 Authorship eligibility guidelines and any intended use of professional writers

The final report will be co-authored by the applicant team with Runswick-Cole, Lead Applicant as Lead Author and other applicants in alphabetical order.

Given the co produced nature of the research we expect that the majority of outputs will be co-authored. Author order will be agreed upon by contributors based on contribution and alphabetical order.

10 REFERENCES

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11. APPENDICIES

11.1 Appendix 1- Required documentation

1. Research Team CVs (included in NIHR application)

Professor Katherine Runswick-Cole

Professor Sara Ryan

Professor Chris Hatton

Dr Patty Douglas

Dr Liz Croot

Clare Kassa

DrRosemary Cisneros

Included in the ethics application

a. Participant information sheets, consent forms (standard format, easy read, community languages)

Work packages 1, 3, 4, 5, 6.

b. Protocols

Distress Protocol

Safeguarding Protocol

c. Confidentiality Agreements

Transcriber

Film maker/ facilitator

Support worker

d. **Film release forms**

participants

people identifiable in films

e. **Data Management Plan**

11.2 Appendix 2 – Schedule of Procedures (Example)

NA - please see project plan

13.3 Appendix 3 – Amendment History

Amendment No.	**Protocol version no.**	**Date issued**	**Author(s) of changes**	**Details of changes made**

List details of all protocol amendments here whenever a new version of the protocol is produced.

Protocol amendments must be submitted to the Sponsor for approval prior to submission to the REC.