



# Gathering Evidence Safely: Cumberland Council's Research Governance Framework

Version: Final Version 1

Date: January 2025

#### **Document version control**

Document information type	Document information detail
Organisation	Cumberland Council
	Gathering Evidence Safely, Cumberland
Document Title	Council Research Governance
	Framework
Filename	
Document Status	Final
Author	Kaz Stuart
Document held by (name/section)	Health Determinants Research
Document held by (name/section)	Collaboration
Contact email	Kaz.Stuart@cumberland.gov.uk
Date of publication	January 2025
Next review date	January 2026
Version Number	1.0
Approval date and by who	Nik Hardy, Colin Cox, Andrew Seekings
	1/11/24
For internal publication only or external	Internal and External
also?	
Document stored on Council website or	Council website and Intranet
Intranet?	

### Document change history

Version	Date reviewed	Reviewed by	Description of revision

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## Context

This is a new framework for Cumberland Council to ensure that all evidence gathering undertaken for research is necessary, ethical, well designed and beneficial to all stakeholders involved.

The Cumberland Council's aim is to improve the health and wellbeing of its residents. As it states in its Strategic Plan (2024-2027):

Health and wellbeing is both broad and complex, involving contributions from and by all Council directorates and all those working in the Council too. Health and wellbeing is at the heart of everything that we do. We want residents to be happy, healthy and safe throughout their lives. We will promote independence, but also make sure we provide help early when needed. When people are vulnerable, our services will support them to live well.

Our central aim of improving the health and wellbeing of our residents is supported by a focus in four key areas. By prioritising and addressing; inequalities, local economies that work for local people, environmental resilience and the climate emergency and delivering excellent public services, we can make an impact on the factors that improve health and wellbeing.

No matter which council directorate we work in, there is a shared responsibility. In understanding how well a service is working, what issues may occur and how to solve them (by understanding what is not working and why something works well) impacts long-term service quality and engagement and is vital in achieving our overarching aims.

To achieve these goals Cumberland Council is committed to making to evidencebased decisions in practice and policy. Generating relevant, timely and meaningful evidence is therefore of great importance to the Council and this policy sets out how we generate this evidence in a structured, consistent, efficient and ethical way. This framework sets out the protocols, procedures and principles by which we gather evidence, underpinned by the following values upheld by the Council:

- Compassionate
- Innovative
- Empowering
- Ambitious
- Collaborative

These values are central to the way evidence gathering is planned, undertaken, analysed and shared and resonate strongly upholding research integrity.

In January 2024, Cumberland Council commenced a five-year Health Determinants Research Collaboration (HDRC) to enable it to focus on achieving health and wellbeing for all, through an evidence-based approach. The HDRC team are in place

to support evidence gathering and evidence use across the Council. For the next five years this team will own this framework and will be central to managing research activities.

### Purpose

The Cumberland Council Research Governance Framework is designed to support staff to gather evidence safely, conduct rigorous and credible research that can inform policies, strategies and support decision-making. The Council's Research Governance Framework guidance defines clear standards and procedures of good practice to maximise quality and consistency and reduce risks associated with conducting research (both on a practical level but also accurate interpretation and therefore decision-making), including any potential arising risks that may affect the Council. This framework will ensure:

- Safe collection and collation of evidence to further the work of the Council
- Avoidance of duplication where evidence already exists
- The protection of residents, Council staff and the Council from harm
- Generation of high-quality evidence to enable the Council to make sound and robust decisions.

The use of evidence is a key building block in the development of both policy and practice, ensuring that we better meet the needs of the people we support in the most inclusive, effective and efficient ways and ensuring all evidence gathering is rigorous, representative and credible.

Professional bodies have their own frameworks for research governance and this framework has taken them all into consideration. The work of the Council falls under the remit of the Health Research Authority and the Department of Health and Social Care. As the HDRC is funded by the National Institute of Research it must adopt The UK Policy Framework for Health and Social Care Research, and this 'Gathering Evidence Safely: Cumberland Council Research Governance Framework' is written in accordance with this and other professional bodies' research governance frameworks to ensure that all Council activity are protected across all directorates.

### Definitions

**Community Engagement** is the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people. Communities can be engaged in participating, designing, conducting, analysing and sharing the findings of evidence gathering.

**Consultation** is the systematic collection of views on a range of options, solutions, or potential decisions. Consultation aims to gather input to inform decision-making or to ensure that a proposed action is acceptable to those affected.

**Evidence** is any information or data that supports or disproves a claim, hypothesis or argument. It is the basis for making decisions, drawing conclusions, and establishing the truth or validity of a statement. Evidence can be presented in any form, for example; data, statistics, facts, case studies, evaluations, opinions and beliefs, images and artefacts, documents, policies and previous research. It is anything collected in support (or denial) of a decision.

**Evidence-base** refers to a collection of evidence which underpins a particular decision, practice or policy.

**Evidence Gathering** can take different forms. The process of gathering evidence is usually referred to as 'research', which is defined below. Cumberland Council deliberately use the term evidence gathering rather than 'research' as many staff who collect evidence may not think of themselves as 'researchers'. The term evidence gathering is also deliberately broad to ensure it encompasses as much activity as possible.

**HDRC** refers to the Health Determinants Research Collaboration Team. The HDRC is funded by the National Institute of Health Research from January 2024 to December 2028. The HDRC team's purpose is to embed evidence-based practice, evidence-based decisions and evidence-based policy into all Directorates in the Council.

**REEL** stands for 'Research, Evidence, Evaluation and Learning' and is a term used describe the activities the HDRC is developing in the Council and community partners. This is supported by our capability framework, training programme and developing Evidence Hub.

**Research** is defined by the UK Policy Framework for Health and Social Care Research as "the attempt to derive generalisable or transferable new knowledge to answer or refine relevant questions with scientifically sound methods". Primary research involves gathering new data. This is higher risk than secondary research which involves synthesising and analysing existing data. Research includes the use of qualitative and quantitative data collection methods, in a wide range of ways from limitless number of sources. Evidence gathering is a key activity in research.

**Research Ethics** refers to the moral principles guiding research from its inception through to completion and publication of results, keeping both the research participant and researcher safe, emotionally and physically.

**Research Ethics Committee** refers to a multidisciplinary, independent body responsible for reviewing research proposals involving human participants to ensure that their dignity, rights and welfare are protected. The independence and competence of a REC are based upon its membership, its rules regarding conflicts of interest and on regular monitoring of and accountability for its decisions.

**Research Governance** is a process of ensuring the quality of research and for protecting the rights, dignity, safety and wellbeing of those involved.

**Research Integrity** refers to all of the factors that underpin good research practice and promote trust and confidence in the research process.

**Risk** refers to the potential for harm, negative outcomes, or adverse consequences that may arise as a result of the research process. This harm or negative impact could be physical, psychological, social, financial, or reputational in nature, and it may affect participants, researchers, or other stakeholders. risks are often weighed against the potential benefits of the study. Researchers must demonstrate that the knowledge gained or the benefits of the research justify any risks involved. This principle is central to ensuring that the research is ethically sound and scientifically valuable.

## Scope

This framework encompasses the research activity of all staff at the Council, all research done on behalf of the Council by outside agencies and all forms of research.

This Research Governance Framework does not include the routine collection of management information or information collected in the course of normal practice and those used as part of day-to-day practice. Nor does the Research Governance Framework include consultations.

Consultation is the systematic collection of views on a range of options, solutions, or potential decisions. Consultation aims to gather input to inform decision-making or to ensure that a proposed action is acceptable to those affected. Consultations tend to be quantitative, using techniques like surveys. It may also involve activities like meetings, surveys, public forums, and focus groups. Consultation is more about gathering perspectives rather than generating new knowledge. In some cases, the council has a legal duty to consult before making changes to policies or services. Consultations have a clear remit and 'start and end' points. However, they can still form part of an ongoing period of engagement and a formal decision-making process. Details of how to conduct consultations can be found in <u>Cumberland</u> <u>Council's Community Engagement Framework</u>.

In contrast, research involves systematic investigation to establish facts, develop new theories, or apply existing knowledge in new ways. It aims to generate new knowledge or insights. Research includes evidence gathering activities like experiments, surveys, data analysis, and literature reviews. Research can be basic (to increase understanding) or applied (to solve specific problems). The outcome of research is often published in academic journals, reports, or used to inform policy and practice.

The framework applies to all new evidence gathering activity. Evidence gathering is the process of 'doing research'. Evidence gathering has many different purposes, formats and outputs. Therefore, this framework provides appropriate and proportionate planning and control protocols to these different forms of evidence gathering.

The framework applies to external organisations, researchers and students wanting to partner with Cumberland Council and/or access staff or residents through Cumberland Council, including Council staff conducting research as part of their own training.

Anyone starting a new evidence gathering project must register this work with the HDRC team, assess the level of risk it poses and plan to mitigate those risks according to the total risk level. The review only needs to be done once for a group that is ongoing (e.g. service user advisory group).

Research Governance covers new evidence gathering, internally and externally funded projects and projects carried out in-house or by people employed by other organisations.

### **Principles**

Cumberland Council uphold the UK Concordat for Research Integrity principles for good research. These include:

- Upholding the highest standards of rigour and integrity in all aspects of evidence gathering and research honesty, rigour, transparency, accountability, care and respect.
- Ensuring that evidence gathering and research are conducted in accordance with appropriate ethical, legal and professional frameworks, obligations and standards.
- Supporting a research environment that is underpinned by a culture of integrity and based on good governance, best practice, and support for the development of staff as researchers.
- Using transparent, timely, robust and fair processes to deal with allegations of research misconduct should they arise.
- Working together with other agencies and organisations to strengthen the integrity of evidence gathering and research and to review progress regularly and openly.

In addition, Cumberland Council is committed to:

- Community engagement and empowerment in evidence gathering activities, designing, conducting, analysing and reporting evidence themselves.
- Open and transparent reporting that enables knowledge to be mobilised into practice that is used and understood by everyone.
- Ensuring benefit for all, including both participants and staff who should benefit from the experience and outputs of evidence gathering. Involvement in evidence gathering should be supported by skill and knowledge development for all involved, it builds confidence and experience and has potential to generate evidence that benefits everyone.
- An inclusive view of evidence and research. All methods of evidence gathering and all forms of evidence are equally valued. Judgement on what is 'good' evidence gathering hinges on the fit between the question being asked and the approach or method used to answer it.
- Supporting the professional development of staff with skills in evidence gathering, evaluations and research and career progression enhanced with research experience.

## Cumberland's Evidence Gathering Protocol

All new evidence gathering activity will be taken through the framework. Some evidence gathering just needs to be registered whilst others will need to undergo a more thorough preparation and review period. The evidence gathering protocol helps you through this process.

#### Stage 1: Registering Your Idea

All evidence gathering should be registered on the Cumberland Council's Evidence Register. To do this you need to complete the Evidence Gathering Registration Form which will ask staff to add the basic details of a project and ask you to assess the project in terms of the sensitivity of the topic and the vulnerability of the people it hopes to engage. The HDRC team will let you know if we know of other research of a similar nature from our register of research.

These combined scores give three levels of risk which determine how much preparation and review the evidence gathering will need.

Sensitivity of the <b>topic</b> or <b>subject</b> of the	4 Highly Sensitive	4	8	20
evidence gathered	3 Medium Sensitivity	3	6	15
	2 Low Sensitivity	2	4	10
	1 Not Sensitive	1	2	5
		1 No People are Involved	2 Low Vulnerability	5 High Vulnerability
	Vulnerability of the <b>person</b> providing evidence			ence

The table below shows how risk is assessed for evidence gathering activity.

Figure 1: Evidence Risk Assessment Matrix

#### Sensitivity of the subject of the evidence gathered

Does the engagement/project ask individuals to provide information about themselves and their views?

**4 - Highly sensitive** Evidence about 'race' or ethnicity; political opinion; religious, spiritual or other beliefs; physical or mental health conditions; sexuality and/or gender identity; abuse (child, adult); nudity and the body; criminal activities; political asylum; conflict situations; personal violence; and terrorism or violent extremism.

**3 – Medium sensitivity** Confidential- Evidence includes confidential information such as beliefs, motivations and behaviours.

**2 – Low sensitivity** Private- Evidence includes private information such as perceptions of services.

**1 – Not sensitive** Public- Evidence gathering seeks to collate factual information that is held open access e.g. census data or national statistics.

#### Vulnerability of the person providing the evidence

Vulnerability may arise as a result of a developmental stage, cognitive impairment, limited knowledge of the language, social status, dependent or subordinate position relative to the person or institution requesting information, historical treatment or expectation of benefit or negative repercussions that may affect their ability to provide informed consent.

**3 – High vulnerability** People are involved in the evidence gathering whom you anticipate have vulnerabilities, for example; children aged under 16; those lacking mental capacity; or individuals in a dependent or unequal relationship, or who have prior experience of psychological or physical harm or adversity in its broadest sense.

**2 – Low vulnerability** People are involved in the evidence gathering who have no evident or obvious vulnerabilities.

**1 – No people are involved** Evidence gathering involves no people and does not draw on anything said or created by people e.g. a literature review or evidence review.

Risk in evidence gathering is not restricted to the participants and the topic of evidence. There may also be risk due to new or controversial methods of data collection being used or due to the places a member of staff might visit in order to gather data. There is space to comment on these risks in the Stage 1 application form.

Once staff have submitted the Stage 1 Evidence Gathering Registration Form the HDRC / Research team will review it and schedule a short meeting to discuss the outcome.

If the evidence gathering has a low risk (a score of 1-3) staff will be informed they may proceed to Stage four without further action. If the risk level higher than 3, the staff will be asked to complete a Stage 2 Evidence Gathering Application Form to enable the HDRC / Research team to better review and support the project and to mitigate any risks.

Stage one will take no longer than 2 weeks.

#### Stage Two: Writing your Research Proposal

All evidence gathering with a risk score of four or higher needs planning in more detail in order to mitigate risk. This is done on the Stage 2 Evidence Gathering Proposal Form.

For evidence gathering risk scores between 4 and 10 the staff members line manager and the HDRC team will review the Stage 2 Evidence Gathering Proposal Form and advise the staff member on whether to proceed with the activity or to amend the proposal.

For evidence gathering risk scores of 11 or more the staff members line manager, Assistant Director or Director, the HDRC Manager and an Academic partner will review the Evidence Gathering Proposal form and advise the staff member on whether to proceed with the activity or to amend the proposal.

If amendments are requested the lead staff member will need to complete and resubmit the form.

If the evidence gathering proposed is high risk or based in an NHS setting, the project may be progressed to a Stage 3 University or NHS Ethics Committee.

The staff member is expected to inform the stakeholders about the outcome of Stage 2.

In situations where a proposal is rejected, a member of the HDRC/Research team will meet with the relevant project lead staff member(s) to discuss the issue. Stage two will take no longer than three weeks.

#### Stage Three: Applying for Wider Ethical approval

Where appropriate projects may need to seek further ethical approval from either the University of Cumbria (Cumberland Council's research partner), and / or register with the Integrated Research Application System (IRAS), the NHS research portal and ethics system. The documentation provided for stage two gives the majority of the information needed to do this.

This may be the case when the people involved, the subject or method are high risk, if the work is taking place in a health care setting, or if the research findings are going to be published in an academic journal.

The HDRC Team will assist staff in preparing these documents and ensuring adherence to the correct protocols.

Receiving a review from an external ethics panel can take up to six weeks from submission.

#### Stage Four: Conducting your Project

Stage Four is where staff proceeds to carry out their evidence gathering project, adhering to the approved plans and protocols. If plans change or ethical issues arise, the lead staff member must report them to the HDRC / Research Team.

### Stage Five: Completing your Project

Once the research is completed, the lead staff member will notify the HDRC Team using the short Stage Five Evidence Gathering Completion Form.

This form asks staff to summarise the successes, difficulties, and lessons learned from the project along with a brief summary of the findings. The HDRC Team will also request a copy of the final output so it can be added to the Cumberland Council Evidence Hub.

This process is summarised in the following flow chart:

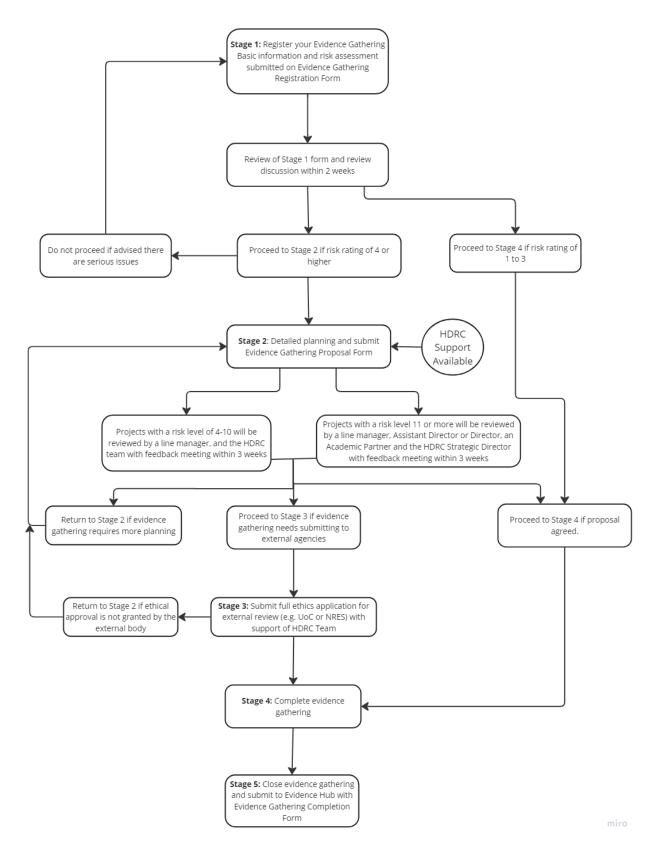


Figure 2: Evidence Gathering Flow Chart

### **Roles and Responsibilities**

**Staff member** All staff are responsible for following the Gathering Evidence Safely Framework and protocols.

**Line manager** An individual's line manager will be responsible for confirming evidence gathering is in line with directorate priorities and for reviewing proposals with a medium or high-risk level.

**Assistant Director/ Director** The Assistant Director or Director will confirm the evidence gathering is in line with directorate priorities and will review proposals with a medium and high-risk levels respectively.

**HDRC Team Members** HDRC team members will review all Evidence Gathering Registration Forms and Evidence Gathering Proposals with a medium level of risk and will feedback the outcome of the review within two and three weeks respectively.

**HDRC Research and Innovation Manager** The HDRC Manager will review all proposals with a high-risk level and updates the Evidence Gathering Safely Framework annually.

## **Ethical Principles**

While these ethical principles and guidance aims to be comprehensive, they do not claim to provide an answer to every ethical dilemma you may face. While it's important to identify and resolve ethical issues and concerns before research gets underway, it's not always possible to anticipate these. The HDRC team are always available to help staff discuss live ethical issues which might not have been anticipated.

Ethical conduct in evidence gathering is, in essence, the application of informed moral reasoning, founded on a set of moral principles. These are set out below:

**Respect-** The dignity and rights of participants must be at the forefront of the evidence gathering.

**Consent-** There must be appropriate arrangements for ensuring the people involved understand what they are asked to do (information to participants template), for ensuring they can give informed consent (consent template) and mechanisms in place for participants to withdraw from the study if they so wish.

- **Transparency-** Some evidence gathering might involve an element of risk to those participating in it. Risk must always be kept to a minimum, be identified explicitly and explained clearly.
- **Confidentiality-** Attention must be given to ensuring confidentiality of personal information, this includes making sure people are not identifiable by name or circumstance.
- **Incentives and reward-** Attention must be given to appropriately incentivising or rewarding participation in evidence gathering activities that will not bias or prejudice participation.
- **Culturally sensitive-** Staff should respect the diversity of human culture and conditions and take full account of ethnicity, gender, disability, age, economic status and sexual orientation in the evidence gathering and reporting.
- **Well-designed-** The design and procedure of evidence gathering are clearly described and justified in a proposal, where applicable conforming to a standard template and/or specified contents.
- **Health and Wellbeing-** Evidence gathering activity should ensure the health and safety of participants and staff and should also give each the opportunity to grow and develop.
- **Resourced-** Ensuring all evidence gathering has appropriate resources to ensure its success. Research governance itself is costly and we recommend that governance costs into the cost of a proposal £100 for projects under £5000 and £1000 for projects over £500,000.
- **Insurance and indemnity-** Adequate (Special provision is not expected unless existing arrangements (e.g. professional insurance, membership of NHS Litigation Authority schemes) provide inadequate cover) provision is made for insurance or indemnity to cover liabilities which may arise in relation to the design, management and conduct of the project.
- **Open access-** Allowing for free access to information on current and completed evidence gathering projects via the Cumberland Council Evidence Hub.
- Avoidance of duplication- It is essential that existing sources of evidence, especially literature searches/ systematic reviews, be considered carefully prior to undertaking new evidence gathering. Research which duplicates other work unnecessarily or which is not of sufficient quality to contribute something useful to existing knowledge is in itself unethical and wasteful of resources.
- **Environmental Respect and Sustainability-** Staff must design and execute projects with a view to creating no greater negative environmental impact than is absolutely necessary. This includes but is not limited to avoiding making carbon-creating journeys where alternative means of interaction are entirely

feasible, avoiding printing of transcripts and questionnaires where electronic formats are equally practical, and using online interfaces for surveys rather than distributing large numbers of email attachments.

**Reciprocity-** Evidence gathering (wherever feasible) should be based on dialogue between staff(s), participant(s) and any public/community groups who may be involved in - or impacted by - the outcomes. To this extent, community concerns should be actively and transparently incorporated into research at all stages, from initial design to final dissemination, and staff should ideally seek to ensure that results can be used for the common good. An explanation of contexts where reciprocity is feasible but impractical should be set out in a full Evidence Gathering Proposal.

Any evidence gathering project that reaches the Stage 2 evidence gathering proposal will consider all aspects of ethical approval and prepare a draft participant information, consent and debrief form.

Further guidance on ethical considerations can be accessed on the Cumberland Council REEL Toolkit (in development) and from our REEL Training Programme.

### Safeguarding

**"Safeguarding"** is defined as "protecting people's health, well-being and human rights, and enabling them to live free from harm, abuse and neglect".

**"Harm"** is the infliction of physical or psychological injury on another person. Harm may be unintentional or intentional.

**"Abuse"** occurs where an individual or a group of people violate someone else's human and civil rights. It may be physical and can involve a criminal offence, but serious abuse also usually involves non-physical (or psychological) abuse.

**"Neglect"** is the persistent failure to meet the basic physical or psychological care needs of a child, other dependant or self.

Situations where safeguarding concerns may be disclosed to a member of staff and / or contractors gathering evidence include:

- face-to-face contact with an interviewer
- telephone contact with an interviewer
- paper responses written on a survey questionnaire and sent through the post
- online or email responses to a survey

If an emergency occurs while a member of Council staff is engaged in their work, they should call the emergency services on 999. As soon as possible afterwards,

they will need to report the action they took to one of the Safeguarding Contacts who will complete the relevant reporting form. If a member of Council staff becomes aware of a person being at risk of harm, abuse or neglect, they will report the issues to the Council Safeguarding Team immediately and proceed as guided by that expert team.

#### Safeguarding Children and Young People

There is no explicit requirement in law for adults to give consent for children's involvement in research nor any single agreement across research organisations about when to seek consent from parents / carers. Cumberland Council draws on the Gillick Competency and Fraser Guidelines and seeks consent from parents or guardians of all children under the age of 16.

The Cumbria Safeguarding Children Partnership <u>Webpages</u> provide more detail on how to safeguard children and young people. If you have urgent concerns for a child, or suspect that a child has been abused in anyway and needs an urgent response, please call the Cumberland Safeguarding Hub immediately on 0333 240 1727.

#### Safeguarding Vulnerable Adults

The Mental Capacity Act 2005 provides safeguards for those who lack the capacity to consent to participate in research. The Act applies to people aged 16 years and over who lack capacity to make a particular decision or take a particular action for themselves at the time the decision or action needs to be taken. Research which is proposing to involve people over the age of 16 who may lack capacity must seek approval to undertake this research from an 'appropriate body', either the Social Care Research Ethics Committee or one of the NHS Medical Research Ethics Committees. In these instances Cumberland Council cannot act as an 'appropriate body'. The Cumbria Safeguarding Adults Partnership <u>webpages</u> provide more detail of how to manage concerns.

### **Evidence Gathering from Social Media**

Careful planning is needed for any evidence gathering that will involve social media and/or human participants recruited/identified through the internet.

For the purposes of this policy, social media are defined by the core components of 'user-generated content, and the possibility of many-to-many communication'.

Social media platforms include Twitter (X), Facebook, video-based sites (e.g. YouTube), blogging sites, discussion forums, online messaging services (e.g. WhatsApp), and similar other platforms that follow from these.

Any evidence gathering that involves private or semi-private online tools for interviews, focus groups or any other data collection techniques also requires careful risk assessment and planning.

Navigating what might be considered 'public' such as the posting of online content and 'private' in terms of identifiable responses to those posts is complex and needs care.

Consent, the right to withdraw, anonymity and identifiability need to be carefully considered where evidence may include quotes or images drawn from social media.

### Transcription

Using an automated transcription tool or paying a professional to transcribe recorded data sets can be cost effective. Any transcription software used must comply fully with GDPR. This is the case for Microsoft Teams, which is recommended as the tool of choice. Other tools should be reviewed to ensure they are GDPR compliant.

If a person is commissioned to transcribe data they will need to sign a confidentiality agreement to confirm they will not discuss the contents of their transcription with anyone. A template for this form is included in the appendices of this document.

Similarly if a translator is hired to facilitate data collection in different languages they will also need to sign a confidentiality agreement.

## Use of Artificial Intelligence

Public Artificial intelligence (AI) may not be used to collect, process, analyse or write up data. Public AI systems are not secure and purposively share content for other uses as such it is not ethical to use them for evidence gathering. If you are considering using a secure AI platform in your project you must seek advice from Information Security and Information Governance and where AI is being considered for processing personal data a Data Protection Impact Assessment must be carried out prior to its use.

## Lone Working

Cumberland Council is committed to the safety of staff who may be travelling alone and working alone in order to gather evidence. <u>Cumberland Council's Lone Working</u> <u>Policy</u> must be followed when gathering evidence in this way.

## **Community Engagement**

Cumberland Council is committed to the active engagement of its community in evidence gathering of all kinds. This includes community members:

- Taking part in evidence gathering as participants
- Supporting Council staff with the design, delivery, analysis and dissemination of evidence as co-researchers

• Leading the design, delivery, analysis and dissemination of evidence with Council staff as co-researchers.

The role community members take will always depend on the context for the evidence gathering, the topic, and the skills and availability of community members, and 'contextual fit' is always the prime consideration when deciding on roles.

Cumberland Council upholds the UK Standards for Public Involvement in Research, namely:

**1.** Inclusive Opportunities - Public involvement partnerships are accessible and include a range of people and groups, as informed by community and research needs.

**2.** Working Together - Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.

**3.** Support and Learning - Offer and promote support and learning opportunities that build confidence and skills for public involvement in research.

**4.** Communications - Use plain language for well-timed and relevant communications, as part of involvement plans and activities.

**5.** Impact - Seek improvement by identifying and sharing the difference that public involvement makes to research.

**6.** Governance - Involve the public in research management, regulation, leadership and decision making.

The process of staff and community members working together to design, conduct, analyse or disseminate research is often referred to as 'co-production'. The NIHR have a set of key principles that Cumberland Council ascribes to for such activities. These are:

- **Sharing of power-** the research is jointly owned and people work together to achieve a joint understanding
- **Including all perspectives and skills-** make sure the research team includes all those who can make a contribution
- Respecting and valuing the knowledge of all those working together on the research- everyone is of equal importance
- Reciprocity- everybody benefits from working together

Building and maintaining relationships- an emphasis on relationships is key to sharing power

These principles are reflected in Cumberland Council's <u>Community Engagement</u> <u>Strategy</u>. Cumberland Council also uses the Relational Principles for Community-Council Partnerships as shown in the figure below. This framework focusses our attention on how we relate to people we work with in the community. It is not just who we work with and which communities they are situated in, but also how we work with them that matters.

Relational Principle	Practice	Behaviours
Accessible	Create	Offer a place that is easy to access and
spaces	accessible and	familiar
	equal spaces	Provide the opportunity for us to access
		information, be heard and debate.
Respect	Be respectful to	Be humble
	our views and	Be open minded
	experiences	Give all voices equal consideration
		Continue to talk to us when we are negative or critical.
Honesty	Be accountable	Be trustworthy and truthful
	and transparent	Be accountable for your decision making
		Make information about decision making easy
		to access.
Commitment	Show	Spend time in your community
	commitment to	Talk to residents
	your community	Offer to help
		Be reliable and responsive
		Be driven by a sense of civic duty

The Relational Principles for Community-Council Partnerships (Wilson, 2024)

Any co-production should have reward and recognition offered and should not leave community members out of pocket. Reward and recognition should be made in line with <u>Cumberland Council's Co-Production Payment Policy</u> which is aligned to the NIHR Payment Guide for Public Involvement. Any deviation from this policy must be clearly justified in an Evidence Gathering Proposal.

Further guidance on community engagement in evidence gathering can be accessed in the Cumberland Council REEL Toolkit and from our REEL Training Programme.

### **Data Protection and Information Management**

All evidence gathering must comply with any requirements of the UK General Data Protection Regulation (UKGDPR) and the Freedom of Information Act 2000 (FOIA).

The UK General Data Protection Regulation requires that personal data are:

a. processed lawfully, fairly and in a transparent manner in relation to individuals;

b. collected for specified, explicit and legitimate purposes and not further processed in a manner that is incompatible with those purposes; further processing for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes shall not be considered to be incompatible with the initial purposes;

c. adequate, relevant and limited to what is necessary in relation to the purposes for which they are processed;

d. accurate and, where necessary, kept up to date; every reasonable step must be taken to ensure that personal data that are inaccurate, having regard to the purposes for which they are processed, are erased or rectified without delay;

e. kept in a form which permits identification of data subjects for no longer than is necessary for the purposes for which the personal data are processed; personal data may be stored for longer periods insofar as the personal data will be processed solely for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes subject to implementation of the appropriate technical and organisational measures required by the GDPR in order to safeguard the rights and freedoms of individuals; and

f. processed in a manner that ensures appropriate security of the personal data, including protection against unauthorized or unlawful processing and against accidental loss, destruction or damage, using appropriate technical or organisational measures.

All information collected through evidence gathering must be recorded, handled and, as appropriate, securely stored in such a way and for such time that it can be accurately reported, interpreted and verified, while the confidentiality of individual research participants remains appropriately protected.

Data is managed in a transparent way that demonstrates commitment to appropriate use for research and protection of privacy in line with <u>Cumberland Council's Data</u> <u>Protection Policies</u>.

It is the staff member's responsibility to ensure there is no unauthorised access to, or disclosure of the data.

Where the processing of personal data is high risk you will consult with the Data Protection Officer to establish whether a Data Protection Impact Assessment is required. The Data Protection Team have this template available for use.

The staff member must check the Cumberland Council Retention Schedule and / or seek clarity on the retention of all documentation related to the evidence gathering from the Records and Retention Officer at <a href="mailto:record.centre@cumberland.gov.uk">record.centre@cumberland.gov.uk</a> / <a href="mailto:Council Retention.gov.uk">Council Retention Schedule and / or seek clarity on the retention of all documentation related to the evidence gathering from the Records and Retention Officer at <a href="mailto:record.centre@cumberland.gov.uk">record.centre@cumberland.gov.uk</a> / <a href="mailto:Council Retention.gov.uk">Council Retention Schedule and / or seek clarity on the retention of all documentation related to the evidence gathering from the Records and Retention Officer at <a href="mailto:record.centre@cumberland.gov.uk">record.centre@cumberland.gov.uk</a> / <a href="mailto:Council Retention.gov.uk">Council Retention and Disposal Schedule available here.</a>

All information must be protected from loss or corruption in an appropriate and approved manner.

Raw data must be held under secure and acceptable conditions and can only be reused with further approval.

Data will not be shared with any organisation unless a Data Sharing Agreement is in place or there is a lawful reason to do so. If you do not have an agreement you must contact the Data Protection Team and use their template. The Council will not pass any personally identifiable data to a third party unless an informed consent has been obtained from the research participants first.

The UK GDPR and Data Protection Act 2018 (DPA) protects the rights of individuals by ensuring the ways in which data are obtained, stored, processed and shared by others is strictly governed. The DPA relates to personal data or information held by organisations about individuals. Failure to comply could result in monetary penalties, enforcement notices, prosecution, reprimands and compensation claims.

Under UK GDPR, individuals (the research participants) have a right to:

- Be informed about the collection and use of their personal data
- Access and receive a copy of their personal data
- Have inaccurate information rectified
- Request their personal data is erased.

If you will be processing personal data (such as a name, address and demographic details) you will need to complete a Data Protection Impact Assessment from available from the Data Protection Team at <u>dataprotection@cumberland.gov.uk.</u>

### **Intellectual Property**

There are various forms of Intellectual Property Rights (IPR), which protect assets such as discoveries, inventions, literary and artistic works, designs and performances. In the context of this Research Governance Framework, Intellectual Property (IP) refers to the ownership of the output of evidence gathering whether that is in the format of a report, presentation, data summary, narrative or more creative output.

Although the legal position is inevitably complex, the law is such that, unless there are specific agreements to the contrary, Cumberland Council would normally be regarded as owning all intellectual property generated by Staff during the course of their employment, or if unpaid, during their work period with the Council.

There are two exceptions to the general rule set out above:

a) The Council may, as a matter of policy, determine those particular categories of IPR should be vested in the staff who produce them. Nonetheless, the Council's capacity to waive its claim to IPR is limited.

b) Some IPR is generated on research or other third-party contracts the terms of which may give third parties (usually the funding body in question) rights over some or all of the IP. (In practice, such third-party rights will be negotiated and documented between the Council and the funding body before the research contract in question is signed.)

### **Reporting and Disseminating Results**

Good research governance supports a culture of evidence informed practice and policy. To further support this culture, and in line with research governance information standards, free access to the information, both on research being conducted and on the findings of the research – positive or negative - is therefore necessary once these have been subject to appropriate review by the HDRC team. This information must be presented in a format understandable to the public.

Any output from evidence gathering should also ensure there is clear and honest attribution and acknowledgement of the direct and indirect contribution of colleagues, collaborators and others in the work produced.

Dissemination must follow Cumberland Council's Communication Protocols in the first instance, and also any protocols agreed by funders and other stakeholders.

Further guidance on disseminating research can be accessed in the Cumberland Council REEL Toolkit and from our REEL Training Programme.

### **Misconduct and Complaints**

Cumberland Council is committed to using transparent, timely, robust and fair processes to deal with allegations of research misconduct should they arise.

Misconduct in evidence gathering includes; failure to notify the Council of any evidence gathering, fabrication, falsification, plagiarism, failure to meet legal or professional obligations, misrepresentation, improper dealing with allegations of misconduct.

Any breaches of this policy, guidance or protocols will be dealt with under the Cumberland Council Staff Disciplinary Procedures.

Any participant or stakeholder can make a complaint about the research through the <u>Cumberland Council's Complaints Procedure</u>. Complaints about the evidence gathering will be dealt with by the HDRC and may lead to the suspension or

cancellation of the project depending on the nature of the complaint. All complaints will be assessed case by case.

### Particular Requirements of Professional Bodies

#### **Children's Services**

Any multi-site research activity in Children's Services which involves four or more local authorities also requires the approval of the Association of Directors of Children's Services (ADCS) Research Group.

#### Health and Social Care

Social care research governed by the Health Research Association and ethical applications are considered via the HRA Social Care Research Ethics Committee.

#### All health and social care settings must uphold the Caldicott Principles:

The Caldicott principles, first introduced in 1997 are a set of good practice guidelines for using and keeping safe people's health and care data. Caldicott guardians support the upholding of the principles at organisational level. All NHS organisations must have a Caldicott guardian, and a wider range of bodies are now expected to have a guardian in place (see below).

The principles are intended to apply to all data collected for the provision of health and social care services where patients and service users can be identified and where they would expect this to be kept private.

- **Principle 1:** justify the purpose(s) for using confidential information.
- Principle 2: use confidential information only when it is necessary.
- Principle 3: use the minimum necessary confidential information.
- **Principle 4:** access to confidential information should be on a strict need-to-know basis.
- **Principle 5:** everyone with access to confidential information should be aware of their responsibilities.
- Principle 6: comply with the law.
- **Principle 7:** the duty to share information for individual care is as important as the duty to protect patient confidentiality.
- **Principle 8:** inform patients and services users about how their confidential information is used and what choice they have. There should be no surprises.

#### **Health Research**

All health research needs to be registered on the NHS Integrated Research Application System (IRAS) at My Research Project. IRAS is a single online system for applying for permissions and approvals for health and social care/community research in the UK. A review through The HRA Research Ethics Service may then be recommended. All research carried out in the NHS is subject to research governance through the NHS ethics committees. This framework is necessarily strict, as it directly influences health outcomes.

The Health Research Authority (HRA) have published a table defining research categorising research, service evaluation, audit and usual practice which can help you decide whether you will need to apply for HRA ethical approval or not: <u>HRA</u> <u>Decision Tool Pdf</u>.

### Applying for External Funding

The HDRC team keep a log of funding opportunities that are regularly available and may be able to find you to identify a funder for your project. You may also internet search for funders, or you may know someone who would fund your work.

There is usually a set of core questions in funding bids and the HDRC team have experience in answering these. Please call on the team for support. The HDRC team can also link you to academics who can help you develop a bid.

Any NIHR grant submitted must have had the support of the NIHR Research Support Service and they will also support you to develop grants for other funders. Please ask the HDRC team for more information.

Initial budgeting and costing for evidence gathering should cover the economic cost of the project and offer value-for-money. Where external funding is sought, it is the responsibility of the Council staff member, with support from the HDRC team, to ensure that rules on eligible costs are followed.

Once you have prepared your grant application you will need to seek approval to submit it. For any grant application under £100,000 you will need a line managers approval to submit. For grants over £100,000 of income you will need an Assistant Director or Directors sign off as per the Cumberland Council Officer Decision Record.

If you are successful in securing your grant you will need the support of the procurement team to develop a contractual agreement with the funder.

Staff members are responsible for the efficient and effective management of allocated budgets for their research in line with the Council's financial procedures and those of any external funding body as may be applicable. Staff members are

responsible for ensuring that allocated resources are utilised in the pursuit of the specified research and not for any other purpose.

### Invitation to be a Participant in a Research Project

You may be approached by another organisation asking if the Council, or a particular team within it can participate in a research project as a subject.

Cumberland Council is committed to supporting third party research wherever it can. A number of practical issues need to be resolved before you can commit the Council to the project. These include:

- **Fit-** does our participation in this project align with our Council and Directorate priorities?
- Benefit- what practical benefits can we gain from participating in this project?
- **Timescales-** do we have the capacity to support the project in the time frame of the project?
- **Costing-** is there a full cost recovery for the Council's involvement in the project and has inflation been added on year on year?
- Payment- how will we access payment for our participation?
- **Data security-** is there a data sharing agreement, data impact assessment or joint data controller agreement in place?
- **Contract-** what will the Council be contractually obliged to do and have our legal team agreed to that?
- Control- will the Council have any control over what is published?
- Identification- will the Council be anonymised or identified in the research?

If you have any questions about agreeing to take part in a project please get in touch with the <u>HDRC team</u>.

### Appendix 1: Evidence gathering registration form

#### **Cumberland Council**

#### Research Governance Framework

#### Stage One: Evidence Gathering Registration Form

Thank you for your interest in gathering evidence to inform your work in Cumberland Council. The HDRC Team are here to support you, please ask if you would like help to complete this form. There are 15 questions and on average it takes 20 minutes to complete.

#### Section One: Basic Details

Project		
Title		

Name of	
Lead	
Council	
Staff	
Role	
Team	
Directorate	
Line	
Manager	

Type of evidence	Evidence review or summary
gathering (highlight all	Evaluation
that apply)	Research
	Consultation or co-production

Type of evidence	<ul> <li>Existing data (secondary research)</li> </ul>
(highlight all that apply)	<ul> <li>Generating new data (primary research)</li> </ul>

Who is leading this	Council
project?	University
	Third Sector
	Other Partner

What do you want to find out? (250 words maximum) How do you plan to find it out? (250 words maximum) How strongly do you think your project links to Cumberland Council's Strategic Plan?	<ul> <li>Very strongly</li> <li>Quite strongly</li> <li>Somewhat</li> <li>Weakly</li> <li>Not at all</li> </ul>
Please explain how this evidence gathering is linked to Cumberland Council's Research Plan, and / or your Directorate Research Plan and / or a Community Panel Research Plan. (250 words maximum)	

Planned start date	
Planned end date	

#### Section Two: Risk Assessment

How sensitive is the subject on which you are gathering evidence? Please highlight the box you think best applies to your project.

4 - Highly sensitive	Evidence about 'race' or ethnicity; political opinion; religious, spiritual or other beliefs; physical or mental health conditions; sexuality and/or gender identity; abuse (child, adult); nudity and the body; criminal activities; political asylum; conflict situations; personal violence; and terrorism or violent extremism.
3 – Medium sensitivity	Confidential- Evidence includes confidential information such as beliefs, motivations and behaviours.
2 – Low sensitivity	Private- Evidence includes private information such as perceptions of services.

1 – Not sensitive	Public- Evidence gathering seeks to collate factual
	information that is held open access e.g. census data or
	national statistics.

How vulnerable are the people you are collecting evidence from / with? Please highlight the box you think best applies to your project.

3 – High vulnerability	People are involved in the evidence gathering whom you anticipate have vulnerabilities, for example; children aged under 16; those lacking mental capacity; or individuals in a dependent or unequal relationship, or who have prior experience of psychological or physical harm or adversity in its broadest sense.
2 – Low	People are involved in the evidence gathering who have
vulnerability	no evident or obvious vulnerabilities.
1 – No people are	Evidence gathering involves no people and does not draw
involved	on anything said or created by people e.g. a literature review or evidence review.

Once you submit this form the data will be entered into Cumberland's Evidence Register enabling everyone in the Council to know what evidence gathering is happening. The HDRC team will review your application form and request a meeting with you within two weeks in order to support you to progress the evidence gathering.

Do not start collecting evidence until you have had agreement it is safe to proceed. For further information please refer to 'Gathering Evidence Safely: Cumberland Council's Research Governance Framework'.

### Appendix 2: Evidence gathering application form

**Cumberland Council** 

**Research Governance Framework** 

Stage 2: Evidence Gathering Proposal Form

Thank you for registering your evidence gathering project. Our joint risk assessment suggests that there is moderate to high level of risk associated with this project and so further planning is needed in order to mitigate these risks. Please complete the form below and the HDRC team will arrange to meet with you within three weeks to discuss next steps.

#### Section One: Basic Details

Project Title	
Reference	
Number from	
Stage One	
Names and Roles	
of Project Team	

#### Section Two: What do You Want to Know?

What is the overall aim of	
your project?	
Please list the questions	
you would want to ask	
people in your interviews/	
survey/ workshops etc.	
Please indicate if these	Exact wording
riease indicate il triese	Exact wording
are exact questions with	
final wording, a draft or	
questions to be asked, or	Draft wording
just areas of interest.	

#### Section Three: About the People Taking Part

Who will you
approach for your
evidence
gathering?
(Please provide
the number of
people and any
demographic
details).
How will you
reach and recruit
these people?

#### Section Four: Mitigating Risks

Are there any	
risks for people	
taking part in this	
project?	
How will you	
manage these	
risks?	
What risks might	
exist for the	
project team and	
how will you	
address them?	

#### Section Five: Benefits

Are there any	
benefits for the	
people taking	
part? If so, what	
are they?	
Do you intend to	
offer any	
incentives,	
payments or	
expenses to	
people taking	
part? If so, what	

and how will they	
be paid?	

#### Section Six: Gathering your Evidence (Methods)

How will you collect your evidence? (Please highlight all that apply)	<ul> <li>Consultation</li> <li>Interview</li> <li>Focus group</li> <li>Workshop</li> <li>Art / dance / drama / music</li> <li>Other</li> </ul>
If 'other' please specify	
How will you analyse the evidence you have gathered?	<ul> <li>Identifying themes</li> <li>Identifying trends and patterns</li> <li>Using examples and case studies</li> <li>Using maths / statistics (e.g. percentages, ranges, averages)</li> </ul>
Please describe how you will engage the community in your project (e.g. designing, conducting, analysing the evidence). If they are not engaged please explain why not.	

## Section Seven: Data Protection and Security

What plan is in place for the storage of data (electronic, digital, paper, etc.)? Will audio and/or	• Yes
video recording take place?	<ul><li>No</li><li>Unsure</li></ul>
If yes, what arrangements have been made for audio/video data storage?	
At what point in the research will tapes/digital recordings/files be destroyed? (Please refer to the Council's Retention Schedule).	

## Section Eight: Sharing your Learning

Will your findings be for internal or external audiences?	<ul> <li>Internal Council Staff Only</li> <li>Restricted external organisations / people</li> <li>Anyone</li> </ul>
What format will your findings take? (e.g. powerpoint, report, video, exhibition)	
Do you intend to publish this evidence gathering in an academic journal or at an academic conference?	<ul> <li>Yes</li> <li>No</li> <li>Unsure</li> </ul>

# Section Nine: Draft participant information sheet Please update this section with your project details.

**Cumberland Council** 

Participant Information Sheet

This template can be adapted for your own project in an electronic or online format, or you can develop your own approach to delivering participant information. Be aware, however, that if an improvised Participant Information Sheet does not cover at least the core of the issues suggested below, reviewers may well ask for significant amendments. Therefore, even if you do not use this template directly, reviewing the sections below may help you clarify appropriate practice for your own project.

The text must be fully accessible for your specific participants, i.e., it must use language that will be unambiguous to that group and avoid unexplained jargon/acronyms. All participant-facing materials should have a clear, consistent and accessible layout (e.g. a sans serif font such as Calibri or Century Gothic and line-spacing set to at least 1.5), and should generally include a Cumberland Council logo and other collaborator/funder logos where relevant. They should also be comprehensively checked for spelling, punctuation and grammar, as they will be available in the public domain and thereby hold reputational significance for all involved agencies.

Please note that in online surveys, the Participant Information and Consent Questions should typically be embedded in the survey itself, and not sent/requested ahead of the survey by email or post in order to maximise participant identity protection and minimise wasted time.

If you are using this template, be sure to remove or reformat all purple (instructional) text- including this header block - and any green (example) text, before finalising and submitting your application for review. **PROJECT TITLE:** The title should be simple and self-explanatory to your participant group, and should appear (in the same form) on all project documentation. In the title, <u>all</u> acronyms need to be written out in full, even where they will likely be familiar to participants.

#### WHAT IS THE PURPOSE OF THE PROJECT?

The background and the aim of the project should be given here. Include a sense of for how long the project will run and a brief outline of the overall design of the project. Be particularly careful to use participant-friendly language here, and to avoid technical jargon unless the participants themselves will be familiar with it. If you know with any certainty, you might also include a note of how many other people will be asked to participate.

#### WHY HAVE YOU ASKED ME TO TAKE PART?

Explain how the project is recruiting participants or how the individual was chosen to take part, detailing all key inclusion criteria. This should align clearly with the previous section, so that it is easy for a participant to understand why they 'fit the bill'.

*For example*: You have been invited to participate in this study because you have identified you are a [X] qualified to at least BSc level, with a minimum of five years of experience working in [Y] since you graduated from your degree, and direct experience of managing [Z].

#### WHAT WOULD TAKING PART INVOLVE?

Explain your methods of data collection, including what the individual will be asked to do (e.g. fill out a questionnaire; keep a diary; be interviewed etc.), how much time will be involved, whether the project involves a one-off involvement or repeat or ongoing encounters, and where the work will take place, e.g. location of interviews. If the project will involve video/audio-recording or photography, explain what equipment might be used and what will be involved for participants, including confidentiality issues. If subsequent publications or other outputs will identify the participant, make sure this is explicit.

*For example*: You will be asked a number of questions regarding [describe research topic and the kind of data you require]. The activity/interview/focus group etc. will take place [in a location / online, and at a time that it is convenient for you, and should last approximately [duration], though you will not be actively cut-off if you feel you have more to contribute. The activity/interview/focus group etc. will be audio-recorded / video-recorded / measured using [detail instruments / equipment].

#### DO I HAVE TO TAKE PART?

Explain that taking part in the project is entirely voluntary, and that participants can withdraw at any time before, during (and where offered) after they contribute without needing to provide a reason. If you are offering the option of *post-hoc* withdrawal, it is essential that a timeframe is also included (usually one or two weeks after the participant's contribution is complete) and to note that methods for withdrawing are discussed below.

If the project is linked to a service that participants are receiving, be certain to reassure them that the service or care they receive will not be affected. Similarly, if they are students, reassure them that their marks will not be affected, whether or not they decide to take part.

<u>For example</u>: It is up to you to decide whether or not to take part. If you do decide to take part, you are still free to withdraw all or any part of your contribution at any time before, during or up to a week after you make your contribution. You can do this without giving a reason and without any impact on any services you are using.

#### WHAT IF I CHANGE MY MIND ABOUT PARTICIPATING DURING THE STUDY?

Reiterate *when* and *how* participants may withdraw from the project, and here it is important to be realistic, to specify timeframes around withdrawing, and to clarify the implications of withdrawing at different stages, during ongoing data collection, or after data collection has been completed. Once data have been redacted and separated from real names, it is very difficult to remove details from a dataset; once an article has been published it is not possible to retract the data. Also, for studies using participants in groups, retraction of one or more contributions after the event can render the wider dataset ambiguous or even meaningless. Finally, the

mechanism for withdrawal must be made unambiguous, and should be attentive to the confidentiality implications of the project itself. Do not, for example, mandate that withdrawal requests from an anonymous online survey be submitted to the researchers by email; this effectively makes breaking anonymity an active condition of withdrawal.

<u>For example</u>: Agreeing to participate in this project does not oblige you to remain in the study or to have any further obligations to the project or team. You can withdraw from the study at any time before or during making your contribution, plus [specify timeframe: up until data analysis begins; for two weeks after the interview; until the end of the funded project; up until publication; until data are deposited in an archive.] If you wish to withdraw, you should [specify mechanism: email / complete withdrawal survey etc.]

If you withdraw from the study, all the information and data collected from you, to date, will be destroyed in line with your wishes, and your name removed from all study-related files.

#### WHO IS ORGANISING AND FUNDING THE RESEARCH?

Explain that you are conducting the research as a postgraduate research student or member of staff at the Cumberland Council. You should explain whether you are the sole project staff, or if there is a team, and name the team. If there is an interview or other direct person-to-person contact with the participant, you should explain who will actually carry out the work with them. You should also state the organisation that is funding the research if appropriate.

#### WHAT HAPPENS TO MY DATA DURING THE PROJECT?

Explain how raw (i.e., unredacted) data will be stored during the project on OneDrive, avoiding the use of mobile storage devices such as external hard drives and thumb drives, and when it will be deleted. Detail who will have access to the raw data at this point and at any time in the future (including stakeholders, funders etc.). Explain (in lay terms) how your storage practices in the project will meet legal requirements of General Data Protection Regulation; funder's requirements; professional bodies; and best practice. Be particularly explicit about the level and

specifics of data redaction/anonymisation that will be applied. Do not propose or imply that qualitative data will be 'anonymous' or 'anonymised', particularly not if you are intending to use direct quotes in any of your outputs. With even redacted quotations, there is a small chance that someone already familiar with a participant may recognise them from their words. This chance increases significantly with the use of focus groups, and 'closed cohort' studies such as those of a workplace or student group. Finally, and to the same ends, be careful to specify if any redacted/anonymous data may be made available either directly through plans to share datasets, or indirectly through any open datasets made public through the project.

For example: Only the project team and a trusted transcriber, signed-up to the full ethical conditions of the project, will see/hear the raw data you provide; these [sound/video] files will not be made available at any time to other individuals or agencies. All your personal details, including names, email addresses etc., will be kept strictly within the research team. When the media files are transcribed, all names, places and exact dates will be removed (redacted).

All raw and redacted project materials will be stored on Cumberland Council's secure, Multi-Factor Authenticated (MFA) SharePoint, in accordance with the General Data Protection Regulation (GDPR) along with the Data Protection Act 2018 (DPA). The project will be also be guided by and adhere to Cumberland Council's data protection policy and guidance. While no raw data will be available to anyone outside of the project team, direct quotations will be used in all outputs from the work and, although redacted, there may be a small chance that someone already familiar with you may recognise you from their content. Redacted transcripts may - in line with some publishers' requirements - also be uploaded in part or in full to an academic data repository.

It is expected that the raw data will be securely deleted as soon as transcription is complete, and by no later than [date]. All redacted data will securely be deleted by [date].

#### ARE THERE ANY POSSIBLE RISKS IN TAKING PART? (WHERE RELEVANT)

Describe any risks or 'costs' to taking part in the project, including the time involved, and if there are possible risks, describe any safeguards or mitigating measures to address those risks. These might include having a friend or family member attend an interview with a participant to provide support, the guarantee of a qualified first aider being in attendance at any project activity involving physical exertion, additional reassurance about spontaneous right of withdrawal and so forth.

<u>For example</u>: The only cost to you here would be in the form of your time. There are no significant risks anticipated from your participation in this project, though it is possible that you may find some of the topics for discussion upsetting. If you anticipate anything being tough for you to discuss, you are encouraged to have a friend or family member with you during the interview for support. If you feel that you need a break during your interview, you need only ask for one. If you need to terminate the interview completely, just say so and you'll need to provide no further reason.

It is difficult to determine all potential risks at the outset of a piece of research, but some potential risks are..."

#### WHAT ARE THE POSSIBLE BENEFITS OF TAKING PART?

Outline any direct benefits for the individual and any other hoped for beneficial outcomes of the project, including furthering our understanding of the topic or sharing experiences with peers (when using such methods as focus groups). Explain any benefits, but where there is no intended direct benefit for the participant, this should be stated clearly. It is important not to exaggerate the possible benefits. For example:

<u>For example</u>: By sharing your experiences with us, you will be helping [staff member name] and the Council to better understand [research topic].

## WILL I BE REIMBURSED FOR ANY OUT-OF-POCKET EXPENSES AND/OR INCONVENIENCES ASSOCIATED WITH PARTICIPATION IN THIS PROJECT?

If you are providing any travel expenses, or small gifts, payments, tokens etc, as recompense for participants' time, please explain this here, and how and when they will receive the expenses/vouchers etc.

#### WHAT WILL HAPPEN WITH THE RESULTS OF THE RESEARCH PROJECT?

Explain what will happen to the results of the evidence gathering. Will they be used in a Council Paper? For which directorate? Will they be published? As articles? A book? A policy briefing? In public engagement or knowledge exchange events? How can they obtain a copy of the final output? Will there be a website? A newsletter for participants? You may not have decided on all of these matters yet, so do try and imagine all the ways you might use the outputs, so that you have relevant consent in the future.

Remember that you cannot use the collected data for any purpose of which the participants have not been informed here, at least not without going back to all of them and seeking further consent. In some studies, not least anonymous online surveys, this will simply not be possible, and therefore any statement you make here will be definitive for the project lifetime.

<u>For example</u>: The results of this study will be firstly published as a formal report for the funders (see above), which will be available on the project website (link). It is then expected that they will be presented at national/international conferences and written-up as articles for peer-reviewed academic journals. We may also use evidence from this study for teaching purposes.

You will be sent a one-page summary of the findings as soon as the project is complete, and notified of when any public outputs become available, including those stored in Cumberland Council's Evidence Hub.

#### WHO HAS APPROVED THIS PROJECT?

Once the project has been approved, update this section to clearly state your approval reference number.

For example: This project has been approved through Cumberland Council's Health Determinant Research Team and / or University of Cumbria Ethics Committee and / or others.

#### SAFEGUARDING AND CHILD PROTECTION

#### This can be deleted if not relevant.

If you tell a member of the project team about something which indicates a risk of serious harm to yourself or other person(s), we may not be able to keep this confidential and will discuss with you what steps we will take.

#### **ENVIRONMENTAL PROTECTION**

This can be deleted/adapted according to the project.

This project has been designed and will be conducted so as to cause minimal negative environmental impact.

#### HOW CAN I FIND OUT MORE INFORMATION ABOUT TAKING PART?

Explain exactly who should be contacted and how, if there is any deadline for making such contact. Where the study will otherwise be authentically anonymous, i.e. a mass survey, either find a way of allowing participants to contact you anonymously (e.g. an online notice board), or make it explicit that by emailing the team directly, they will be breaking anonymity.

#### **PRIVACY NOTICE**

This Privacy Notice explains how we process the personal data of individuals who agree to take part in evidence gathering activity for Cumberland Council [attach statement].

#### WHAT IF I WANT TO COMPLAIN ABOUT THE RESEARCH

If you have any concerns about the way in which the project has been conducted, or you wish to make a complaint, you can use the Cumberland Council's complaints procedure.

#### THANK YOU

Thank you for taking time to read this Participant Information Sheet.

#### DATE

This Participant Information was last updated on: XX/XX/XXXX

#### Section Ten: Consent Form

Please update this section with your project details.

**Cumberland Council** 

#### PARTICIPANT CONSENT FORM

This template can be adapted for your own project in an electronic or online format, or you can develop your own consent-collecting method. Do remember that the text of your consent materials must be fully accessible for your specific participants, i.e., they must use language that will be unambiguous to that group and avoid unexplained jargon/acronyms. Alongside careful wording, this means also adding any additional questions that might be relevant to your project, and deleting any below that are not relevant, as redundant questions could cause significant confusion. Even if you do not use this form, working through the questions below may help you clarify appropriate practice for your own project.

All participant-facing materials should have a clear, consistent and accessible layout (e.g. a sans serif font such as Calibri or Century Gothic and line-spacing set to at least 1.5), and should generally include a University of Cumbria logo, and other collaborator/funder logos where relevant. They should also be comprehensively checked for spelling, punctuation and grammar, as they will be available in the public domain and thereby hold reputational significance for all involved agencies.

Please note that in online surveys, the Participant Information and Consent Questions should typically be embedded in the survey itself, and not sent/requested ahead of the survey by email or post in order to maximise participant identity protection and minimise wasted time.

If you are using this template, be careful to remove or reformat all purple (instructional) text- including this block - and any green (example) text, before finalising your Consent Form and submitting your application for ethical review.

# **TITLE OF PROJECT:** [Project Title – to match exactly that on the Participant Information Sheet]

If you are happy to participate in the project as outlined in the Participant Information, please [initial/check] each box as appropriate, leave blank any box for which you prefer not to give consent, and then [sign this form at the end / move to the main survey]:

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1.	The project staff member has given me my own copy of the Participant Information Sheet, and I have had the opportunity to read and consider the information.	
2.	I have been given the opportunity to ask any further questions and have had these questions answered to my satisfaction.	
3.	I understand that participating in the project involves [describe methods, duration, location e.g. an hour long interview in the participant's own home, or location of their choosing; completing a questionnaire survey 3 times over a 12 month period; committing to ongoing participatory research of approximately 2 hours weekly over 12 weeks; if there is more than one method, or contact point, it may be appropriate to have multiple check boxes for each method or phase of the project].	
4.	I have been given information about how my data will be stored and used during and after the end of the research, and I have read and understood this.	

5.	I understand that the project team will be [taking photographs/videoing] and I give my consent for these [specify data format e.g., photos; videos] to be reproduced for educational and/or non-commercial purposes, in academic publications, reports, presentations, websites and exhibitions connected to the [project name].	
6.	I understand that my data may be quoted in [academic publications, articles, books, reports, web sites, related to the research project: please specify format of outputs if known.]	
7.	I understand that my taking part is voluntary; I can withdraw from the project at any time before or during participation, and I do not have to give any reasons for why I no longer want to take part (and this will be without any impact on any related services I am using). I have read and understood the Participation Information Sheet about the implications of withdrawing at different points during the life of the project.	
8.	I understand that if I want to withdraw from the project, I can withdraw up to <b>xx</b> weeks after by <b>xxxx</b> . I can follow the instructions on the Participant Information Sheet to do so.	

Please sign here if you wish to take part in the project and feel you have had enough information about what is involved:

Role	Name	Signature	Date
Participant			
Parent / guardian if under the age of 16			
Project staff			

#### Section Eleven: Debrief Sheet

# CUMBERLAND COUNCIL PARTICIPANT DEBRIEF SHEET

This template can be adapted for your own project in an electronic or online format, or you can develop your own approach to debriefing participants once their contributions are complete (due to the project ending or the participants withdrawing). Be aware, however, that if an improvised debrief method does not cover at least the core of the issues suggested below, ethics reviewers may well ask for significant amendments. Therefore, even if you do not use this template directly, reviewing the sections below may help you clarify appropriate practice for your own project.

The text of your Debrief Sheet must be fully accessible for your specific participants, i.e., it must use language that will be unambiguous to that group and avoid unexplained jargon/acronyms. All participant-facing materials should have a clear, consistent and accessible layout (e.g. a sans serif font such as Calibri or Century Gothic and line-spacing set to at least 1.5), and should generally include a University of Cumbria logo, and other collaborator/funder logos where relevant. They should also be comprehensively checked for spelling, punctuation and grammar, as they will be available in the public domain and thereby hold reputational significance for all involved agencies.

Please note that in online surveys, debriefing should typically be embedded at the end of the survey itself, and not sent after the survey by email or post to maximise participant identity protection and to minimise wasted time.

If you are using this template, be sure to remove or reformat all purple (instructional) text- including this header block - and any green (example) text, before finalising your Debrief Sheet and submitting your application for ethical review.

# **TITLE OF PROJECT:** [Project Title – to match exactly the Participant Information Sheet and Consent Form]

Thank you for taking part in this project. The study aimed to investigate [insert a very concise reminder of the aim of the project, consistent with that on the PI Sheet, and reveal any deception used].

[Where relevant]: If you subsequently wish to withdraw from this project, [provide a reminder about retrospective withdrawal that is fully consistent with that in the PI Sheet. This should include the number of days/weeks that you have given on the PI Sheet, and remind how they should get in touch with you e.g., by email, with memorable word or number, or using an anonymous Withdrawal Survey, including the link here. Ensure participants are aware that it may not be possible to withdraw their data once analysis is underway etc.].

[Where relevant]: If any of the issues in this study were distressing and you feel you need additional support, please contact one of the organisations below for help:

[Add in appropriate and tailored signposting e.g., you may signpost to support agencies or charities, or you may suggest talking to a GP, an employer or supervisor if relevant].

Participants should be provided with information on how and when they can receive feedback on the results of the project and any information about being able to access results or a summary of findings. For example:

[Where the participants' identities are known to the research team]: When the research is complete, you will be sent a summary of the findings via the channel through which you were originally contacted. If you would prefer not to receive this summary, please let us know using the contact details below. Any future public outputs from the research, such as [include outputs consistent with those described on the PI Sheet, e.g. conference presentations, journal papers] will be made available via Cumberland Council's Evidence Hub.

[Or, for fully anonymous work]: When the research is complete, you will be able to access a summary of the findings via the channels (social media pages, groups,

email lists) on which the project was originally advertised. Any future public outputs from the research, such as [include outputs consistent with those described on the PI Sheet, e.g. conference presentations, journal papers] will be made available via Cumberland Council's Evidence Hub.

#### PRIVACY NOTICE

Privacy Notice for Participants This Privacy Notice explains how we process the personal data of individuals who agree to take part in projects carried out by Cumberland Council. This notice is intended for Participants engaged in evidence gathering activities. It should be read in combination with the participant information sheet and the projects privacy notice.

Thank you again for your time.

[Name the project team, with contact details as per the PI Sheet]

#### Further Considerations for PI/Researcher:

- Ensure that the signposting to additional support is tailored to the specific project and participants.
- Consider how and when the debrief will take place i.e., in person, online or over the phone; at the end of an interview or activity, a week later etc.
- Ensure that there is complete consistency between the debrief sheet, participant information sheet and consent form. If there is not, it may leave the research team vulnerable to complaint.
- If there are multiple stages or phases to the research, you may wish to include details of what will happen next.

# Section Twelve: Confidentiality Agreement for Translators and Transcribers Confidentiality Agreement for the Transcription or Translation of Qualitative Data

Title of Project	
Lead Council Staff:	
Ethical Approval Reference:	

In accordance with the Council Research Governance Framework the identities of all participants in the above-named study must be protected in full accordance with the conditions of ethical approval granted, and all data handled in full compliance with the UK's <u>GDPR</u>. Therefore, any personal information or any of the data generated or secured through transcription must not be disclosed to any third party, unless the permissibility such disclosure has been explicitly approved by the REP.

#### Details of Transcriber / Translator

Name (block capitals):

Address:

By signing this document, I agreeing:

- Not to pass on, divulge or discuss the contents of the audio material provided for transcription to any third parties, unless the permissibility such disclosure has been explicitly approved by the REP;
- To ensure that material provided for transcription is held securely, in full compliance with the conditions of ethical approval granted by the REP, in full compliance with the UK's <u>GDPR</u>;
- To return transcribed material to the research team when completed, by the agreed deadline and in the secure manner approved by the REP;

- To securely destroy any audio/video and other and electronic files provided, and relevant to the above study, immediately after transcripts have been provided to the research team;
- To assist the University where a research participant has invoked one of their rights under data protection legislation;
- To report any loss, unscheduled deletion, or unauthorised disclosure of the audio material to any third parties, to the University immediately;
- To act only on the written instructions of the named Principal Investigator, or a representative of the REP;
- To, upon reasonable request, allow the researcher, or a representative of the REP, to inspect the location and devices where the raw data are stored to ensure compliance with this agreement;
- To inform the University's Data Protection Officer, via <u>gdpr@cumbria.ac.uk</u>, if you believe you have been asked to do something with the audio/video materials which contravenes applicable data protection legislation;
- To not employ any other person to carry out the work, in part or in full, on your behalf.

#### Signature:

#### Date:

# Appendix 3: Evidence gathering completion form

**Cumberland Council** 

**Research Governance Framework** 

Stage Five: Evidence Gathering Completion Form

Thank you for completing your evidence gathering project. We hope you have gained from it and that the end results are helpful to the Council. Please complete the short form below so we can continue to share best practice and evidence across the Council.

#### Section One: Basic Details

Project Title	
Reference	
Number from	
Stage One	

#### Section Two: Summary of the Project

To what extent	
were your aims	
and objectives	
achieved?	
What were the	
main findings of	
the project [no	
jargon or	
acronyms]	
Who can have	Internal Council Staff
access to this	Restricted People / Organisations
work?	General Public
How do you	
intend to share	
your findings?	

#### Section Two: Learning from the Project

What have you learned about the process of gathering evidence?	
What skills, knowledge or experience have you gained as a result of gathering this evidence?	
How can the HDRC or Research process be improved for future Research Teams?	
How supportive or helpful were the HDRC team?	

Please email a copy of the final output to <u>HDRC@cumberland.gov.uk</u> so it can be added to the Evidence Hub.

# Appendix 4: List of Additional Guidance Available (in development)

- How to fill in the evidence gathering forms
- Planning an evidence gathering project
- Different ways of collecting evidence (methods)
- Different ways of analysing evidence
- Sharing your findings
- Writing funding bids
- Ethics and safeguarding research
- Community engagement in research.

# References

Health and Social Caro, Health Descarch Authority	Posoarch Policy
Health and Social Care - Health Research Authority	Research Policy
National Institute for Clinical Excellence (NICE)	Research Governance Framework
British Psychological Society	<u>BPS Guide to Human Research</u> Ethics
British Educational Research Association	Ethical Guidelines
Social Research Association	Research Ethics Guidance
	Evidence, Research and Publication:
	A guide for environmental health
The Chartered Institute of Environmental Health	professionals.
National Institute for Health Research	PPI / governance
Office for National Statistics	Safeguarding Policy
Association for Directors of Children's Services /	An Introduction to Research
REASON	Governance
	Best Practice in Ethics and
West of England Evaluation Strategy Group	Governance of Service Evaluation
	Updated FINAL-the-concordat-to-
	support-research-integrity.pdf
Concordat Research Integrity	<u>(universitiesuk.ac.uk)</u>
	Governance Arrangements for
Department of Health and Social Care	Research Ethics Committees
	UK Standards for Public Invovlement
NIHR and Partners	in Research
NIHR	Guidance on Co-Production
NIHR	Briefing Notes on Public Involvement
NIHR	Payment Guidance
Public Involvement Impact Assessment Framework	PIIAF
Cornwall Council	Research Governance Framework
Tower Hamlets Council	Research Governance Framework
Croydon Council	Research Governance - CYP
	Richmond Research Governance
Richmond Upon Thames Council	Framework
North Yorkshire Council	Research Governance Framework
Islington Local Authority	Ethical Review Process
University of Cumbria	UoC Ethics
University of Cumbria	UoC Code of Practice
UCLan	Ethics Policy and Documents
	Section 12: Research Practice and
National Institute for Health Research Contract	Ethics
Information Commissioners Office	Data Protection Impact Assessments