









### Lincolnshire Research Charter

The **Lincolnshire Research Charter** is a clear, shared agreement between communities and researchers, setting out what both parties can expect when we work together, such as making sure respect, fairness and transparency are built into this.

The **aim** of the Research Charter is to be used to frame research activity, embedded within people's research plans as they engage with communities. We expect communities will challenge researchers if they feel these areas aren't being met.

### Three primary goals:





There are a number of **principles** which together make up the Research Charter. These are split into three key areas:

- Prior to getting involved in research, what's important?
- How do people in research want to feel when taking part?
- What information to share after being involved in research?

These are split into what this means, what this feels like and tips to make this happen from a member of the public / participant perspective and a researcher perspective. The same principle may be applicable throughout the whole process, such as valuing people.



The Research Charter was co-produced with researchers and members of the public, and we thank everyone for their contributions and input into creating something which we'd like to see as a living document, to be adapted and developed over time, but a foundation to how communities and researchers work together.

What's

important

### **Key Principles**

### **Transparency**

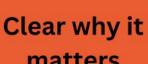
Being open and honest about things so everyone can see and understand what's happening

## Clear expectations and understanding

For everyone to know what to do and what to expect, with no confusion

### Clear Governance

Being clear on the way decisions are made and how rules are followed. including GDPR



To simply explain why something is important and how it makes a difference

### Getting people involved

Encourage people to take part as inclusively and accessibly as possible

# matters

### **Valued**

EMPOWER

NGAGE

Considered important and appreciated by others

Click on each tile to find out what this looks like, how it feels and useful tools, tips and resources!

**Key Principles** 

### Building Rapport

Making a friendly and trusted connection with someone, making them feel comfortable and understood

# Provide learning opportunities

Offering chances or resources to people taking part to learn new skills or gain knowledge

### **Empowered**

Feeling confident and capable to make decisions or take action



Being honest, accurate and ethical when doing research

### Respected

Treated with care and appreciation

## Meaningful Involvement

Ensuring people are taking part in a way that's important, valuable and making a difference

# Good Communication

Sharing information clearly and frequently, making sure everyone understands each other

Click on each tile to find out what this looks like, how it feels and useful tools, tips and resources!

### **Key Principles**

# Research impact

Making sure people understand the results of the research, how their help was used and any benefits

# Sharing findings

Making sure people know what was found



Making sure people know where they can find more opportunities

# Valuing contributions

Recognising and appreciating the contributions people involved have made



# Clear next steps

Being clear what will happen after the research

Click on each tile to find out what this looks like, how it feels and useful tools, tips and resources!

Transparency

**Transparency** is being open and honest about things so everyone can see and understand what's happening.

### What does this look like?

### People / Participant Perspective:

For people to be clear on:

- The purpose of the research (the why)
- · What is involved
- The type of activity
- Support available
- Benefits
- Potential risks

### **Researcher Perspective:**

For researchers to be clear on what people need to know in plain language

For researchers to share contact details for their team members



### How can we make this happen?

- Informed consent process written in an accessible way that includes what is important for people to know
- Include support information that can be available to participants involved in sensitive research such as mental health support resources
- Be clear their involvement is voluntary and they can choose to end their participation should they want to (without having to give a reason)



- Examples of <u>Participant Information Sheet</u> and <u>Consent Forms</u> (NHS Health Research Authority)
- Partnering with the public (NIHR)
- Recommendations for developing accessible patient information leaflets
- UK Standards for Public Involvement





Being **clear why it matters** is to simply explain why something is important and how it makes a difference

#### What does this look like?

### People / Participant Perspective:

For people to understand the benefits of research, the potential impact and the relevance to individuals and communities.

### **Researcher Perspective:**

To be clear why the research matters in plain language. To manage expectations as to the difference the research can make (this could be some time after the project is finished.).

### How can we make this happen?

- Include what are the benefits for both self and / or to others including the wider population
- Include how participant involvement will make a difference
- Include information on how research is relevant to individuals and their communities (e.g. service improvements, better practice, growing the knowledge base, improving care etc.)

# Useful templates, tools and resources to help make this happen

Video from hub





Clear expectations and understanding is for everyone to know what to do and what to expect, with no confusion

### What does this look like?

### People / Participant Perspective:

For people to feel clear what is required of them, including time commitment, flexibility, recognition to take part and criteria (and justifying decisions if exclusions apply), in an accessible way.

#### **Researcher Perspective:**

For researchers to share key information and ensure people understand this fully, including research timescales and communication expectations.



### How can we make this happen?

- Include accessible information on what is required, and if this can be flexible around people's needs, working with participants about the best ways for them to engage.
- Include information in different formats (e.g. large print, different languages, pictorial, aphasia friendly, visual, videos) wherever possible.
- Include how often people will be communicated with, and ensure this is met to maintain relationships with people involved.



- Examples of <u>Participant Information Sheet</u> and <u>Consent Forms</u> (NHS Health Research Authority)
- Example of haPPIE initiative
- NIHR information and accessible health and care research





**Clear governance** is being clear on the way decisions are made and how rules are followed, including GDPR.

#### What does this look like?

### People / Participant Perspective:

For people to be confident they know what is happening with the information they provide.

### **Researcher Perspective:**

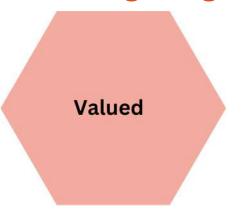
For researchers to share accessible, key information and ensure people understand this fully, including required commitment, research timescales and communication expectations.

### How can we make this happen?

- Share what information (data) will be collected, how it will be used, shared, stored, retained and disposed of.
- Share information on how as a researcher, you will protect personal data and maintain confidentiality.
- Share participant opportunities to be part of the project governance, such as steering group membership, experts by experience advisory groups etc.
- Share information on research governance process and ethical approval (if appropriate)

- <u>Principles of good practice</u> in the management and conduct of health and social care research
- NIHR race equity framework





**Being valued** is being considered important and appreciated by others.

### What does this look like?

#### People / Participant Perspective:

For people to feel appreciated, recognised and valued for their time and contributions to research activity.

#### **Researcher Perspective:**

To show you genuinely appreciate the time people have taken to participate in research activity.



### How can we make this happen?

- Awareness from researches they need experiences and insights from participants, to gain local context and break down any hierarchy between researchers and communities.
- Recompense participants for their time wherever possible, and be clear with people what this looks like before they take part in research.
- Consider how to recompense people in a way that works for them.
- Acknowledge contributions made by participants, such as included in research reports, publications etc.



- NIHR Recommended rates for time and involvement
- MRC
- · Arts and Humanities Research Council
- Economic and Social Research Council

### Getting People Involved



**Getting people involved** is to encourage people to take part as inclusively and accessibly as possible.

#### What does this look like?

### People / Participant Perspective:

For people to have different opportunities to get involved in research throughout the research process such as designing information leaflets, sharing the findings, or sitting on a steering group.

#### **Researcher Perspective:**

For researchers to offer meaningful, inclusive and flexible ways to participant, with a willingness to listen approach, and support people to get involved.

### How can we make this happen?

- Include clear ways people can get involved in meaningful, inclusive and flexible ways.
- · Work with people to understand and make full use of their skills and experience
- Be clear how as a researcher you will keep people informed at different stages of the research process, and stick to these.

- <u>Example of Bristol research information</u> for the public
- NIHR Shared commitment to public involvement resources
- NIHR ARC West's resources
- NIHR resources partnering with the public





**Clear next steps** is being clear what will happen after the research.

### What does this look like?

#### People / Participant Perspective:

For people to understand how research results and recommendations will be shared, and what will happen afterwards.

#### **Researcher Perspective:**

For researchers to be clear what will happen after the research, how the findings will be shared and what will come next.



### How can we make this happen?

- Researchers can think about ways to work with participants in the developing accessible materials
- Outline what will happen after the research is completed clearly with no confusion, in plain language
- Share research results and recommendations, giving genuine consideration to participant involvement in dissemination.
- Ensure research results are in plain language, translated where appropriate
- Include who / where the research will be shared

Share information on any follow-on research, including practicalities (eg contact details)

on how to stay involved



research activity?



### What does this look like?

# Honesty Trust Respect

**Building rapport** is making a friendly and trusted connection with someone, making them feel comfortable and understood.

### People / Participant Perspective:

For people to feel listened to, understood and comfortable to share their experiences.

### **Researcher Perspective:**

For researchers to build trust through keeping your word and doing what you say you will to create a good relationship and have rapport with people.

### How can we make this happen?

- Agree boundaries with yourself on whether you will share any personal information
- · Acknowledge relationships are key to research activity with communities
- Acknowledge every contribution is valuable
- Do what you say you are going to do, when you said you were going to do it by



research activity?

Research integrity

**Research Integrity** is being honest, accurate and ethical when doing research.



### People / Participant Perspective:

For people to feel informed and confident at all stages of the research process through timely updates, including being clear about the analysis process.

### **Researcher Perspective:**

For researchers to share accessible information at all stages of the research process, including the analysis process.



### How can we make this happen?

- Share accessible information on what people can expect during their time in the research process, including when they can expect to hear from the research team. Ensure these timelines are stuck to, and if they can't be, be honest with participants and let them know.
- Acknowledge sometimes when things don't go as planned, learning can still be had
- Follow all ethical guidelines related to your research activity



# Useful templates, tools and resources to help make this happen

 Learning area on the Lincolnshire Research & Innovation Hub

Meaningful Involvement



**Meaningful involvement** is ensuring people are taking part in a way that's important, valuable and making a difference.

#### What does this look like?

#### People / Participant Perspective:

For people to feel they are making contributions to something worthwhile.

### **Researcher Perspective:**

For researchers to be clear on the purpose of research, the value of their contribution and involvement and well-planned.

### How can we make this happen?

- Involve people early in planning and decision-making wherever possible
- · Ask their input, shaping questions, methods or focus areas
- Be clear what their contributions will lead to

- · National standards for inclusivity
- <u>Public involvement in research impact</u> toolkit (PIRIT)
- Why reaching out to communities is key



research activity?

**Empowered** 

**Empowered** is feeling confident and capable to make decisions or take action



#### What does this look like?

#### People / Participant Perspective:

For people to feel they bring valuable insight and knowledge, and encouraged to learn and ask questions.

#### **Researcher Perspective:**

For researchers to share accessible information at all stages of the research process, including the analysis process.

### How can we make this happen?

- Give people time to ask questions
- Regularly ask if people need anything clarifying
- Be neutral, unbiased and non-judgemental
- Consider where as the researcher, you are engaging with communities and how the space feels



research activity?





**Respected** is ensuring people are treated with care and appreciation

#### What does this look like?

### People / Participant Perspective:

For people to feel respected and treated with care, kindness, compassion and accepted in a safe and comfortable environment.

#### **Researcher Perspective:**

For researchers to treat all involved with respect, dignity and acceptance.

### How can we make this happen?

- Include information on how to withdraw from the research at any point
- Researchers to be prepared in advance, organised and be on time
- Consider the venue, ensuring it is accessible, comfortable, suitable parking and welcoming
- Actively listening, showing genuine interest





research activity?

**Good communication** is sharing information clearly and frequently, making sure everyone understands each other.



### People / Participant Perspective:

For people to know what's happening throughout the research process

### **Researcher Perspective:**

For researchers to keep people in the loop throughout the whole research process



### How can we make this happen?

- Share information on what people can expect
- Do what you say you are going to do



# Useful templates, tools and resources to help make this happen

• Live Illustration

Provide learning opportunities



**Provide learning opportunities,** offering chances or resources to people taking part to learn new skills or gain knowledge.

### What does this look like?

### People / Participant Perspective:

For people to have access to learning opportunities if they would like

### **Researcher Perspective:**

For researchers to offer opportunities to develop additional skills and knowledge where possible

### How can we make this happen?

• Consider areas where participants could learn additional skills (e.g. data analysis)

- Lincolnshire Research & Innovation Hub
- NIHR Learning area
- PPI Senate Information
- LORIC





**Research Impact** is making sure people understand the results of the research, how their help was used and any benefits

#### What does this look like?

#### People / Participant Perspective:

For people to know the outcomes of the research, how their contributions and input have been used and the benefits to communities / individuals.

### **Researcher Perspective:**

For researchers to make sure people understand the results of research, in accessible formats



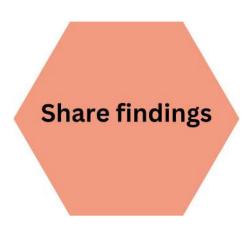
### How can we make this happen?

- Share an early draft with participants to 'sense check', encouraging questions and feedback
- Present findings in accessible formats, considering different styles and publication formats
- Ensure all participants receive the report which includes findings, outcomes and a clear summary
- Providing an opportunity for participants to shape the sharing of the research report or findings



# Useful templates, tools and resources to help make this happen

 <u>Public involvement in research impact</u> toolkit (PIRIT)





**Share findings,** making sure people know what was found.

### What does this look like?

### People / Participant Perspective:

For people to be involved in sharing findings of the research they were involved in.

### **Researcher Perspective:**

For researchers to provide opportunities for people to comments on reports, ask questions and involved in disseminating findings

### How can we make this happen?

- Consider creative and accessible ways to share findings of the research
- · Ask participants how they can support with dissemination

- Lincolnshire Research & Innovation Hub
- <u>Learning section on Research &</u> <u>Innovation Hub</u>



Further research opportunities

**further research opportunities,** making sure
people know where they can
find more opportunities



#### What does this look like?

#### People / Participant Perspective:

for people to know what opportunities there are to stay involved in the research, or getting involved in other research studies.

#### **Researcher Perspective:**

For researchers to share other opportunities to get involved in research

### How can we make this happen?

- Include information on opportunities to stay involved in the research
- Details on how participants can support disseminating research outcomes
- Promote other opportunities, such as Lincolnshire R&I hub, Be Part of Research, Join Dementia Research etc.



- Leaflet on R&I hub
- Join Dementia Research
- · Be Part of Research





**Valuing contributions,** recognising and appreciating the contributions people involved have made.

### What does this look like?

### People / Participant Perspective:

For people to feel their contributions had been valued, appreciated and recognised.

#### **Researcher Perspective:**

For researchers to show genuine appreciation in thanking participants for their participation and where to seek advice and support following research

### How can we make this happen?

- Thank participants for their time and contributions
- Ensure all participants have been recompensed as agreed at the beginning
- Acknowledge contributions within the reports
- Share information on how to seek and advice and support if required post-study



Clear Next Steps

**Clear next steps** is being clear what will happen after the research.

### What does this look like?

### People / Participant Perspective:

For people to understand how research results and recommendations will be shared, and what will happen afterwards.

### **Researcher Perspective:**

For researchers to be clear what will happen after the research, how the findings will be shared and what will come next.



### How can we make this happen?

- Researchers can think about ways to work with participants in the developing accessible materials
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- Share research results and recommendations, giving genuine consideration to participant involvement in dissemination.
- Ensure research results are in plain language, translated where appropriate
- Include who / where the research will be shared
- Share information on any follow-on research, including practicalities (eg contact details) on how to stay involved



### **Additional Useful Links and Information**

#### Click on the titles to learn more

**Explaining the Social Determinants of Health** 

Performance-based readability testing of participant information

Going the extra mile: Improving the nation's health and wellbeing through public involvement in research

Improving how we work with patients, carers and the public

NIHR learning for involvement - training and resources for public involvement in research

Briefing notes for researchers - public involvement in NHS, health and social care research

Public co-applicants in research - guidance on roles and responsibilities

People's Voice Media