CARE HOME RESEARCH AN INTRODUCTION FOR CARE HOME STAFF

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Introduction

This resource has been produced for care home staff – domestic, care, ancillary, administration, catering and estates teams – to develop their understanding of what is involved in research in care homes. It will provide staff interested in research in care homes with an overview of what research is and how it could benefit them and the residents they care for.

The guide was commissioned by Iriss and written by **Maria Drummond**, Senior Clinical Studies Officer with ENRICH Scotland. It follows **Enabling Research in Care Homes**, a workshop held in September 2021, hosted by Iriss and ENRICH Scotland. The workshop provided a space to share experiences and explore issues about care home research with an audience of practitioners, academics and researchers.



Structure

The guide is comprised of six sections:

- **Section 1** introduces what research is (and is not) and outlines the various activities involved, including planning, designing, data collection, analysis and sharing findings.
- **Section 2** highlights the benefits, challenges and practicalities of care home research.
- **Sections 3** and **4** are based on interviews with a researcher and a care home staff member. These conversations provide details of their experiences with care home research.
- **Section 5** explores the importance of partners in research, including those with lived experience.
- Section 6 looks at ways care home staff can get involved in research.

Sections include prompts and quotes from those involved in care home research, to encourage reflection and to help put key concepts in context.

Outcomes

Those who use this resource will gain:

- Understanding of what research is (and is not)
- Knowledge of how research is carried out in care homes
- Improved confidence in accessing and understanding care home research





Research is a popular word that is often misunderstood. Thinking about 'doing research' might conjure up images of people in white coats working in laboratories who are 'trying to find the cure for cancer', but research can investigate almost anything and everything. Research is the process of answering questions that have not been asked before or answering existing questions in new ways. This creates new knowledge that should be beneficial to those involved and wider society. Researchers might aim to understand experiences, ideas or groups of people with specific characteristics. Where there is a question, there is research to be done!

What is not research?

Sometimes research can be confused with evaluation or improvement processes, such as audit or quality improvement. An audit measures performance against existing protocols or guidelines; quality improvement aims to understand existing approaches to find ways to improve them. These activities can inform research but are different.

Historically, the value and importance of care home research have been overlooked, although there have been important studies in care homes. The devastating effect of COVID-19 highlighted the need for practice guidelines in care homes that consider the realities of the unpredictable, variable and homely environment. Increasingly, these guidelines are informed by research done with care home staff and residents.

Research carried out in or related to, care homes can involve staff, residents and their families. Participation can happen in different ways. It might be as simple as completing a survey or questionnaire or being interviewed individually or as part of a group. Or it could be something like seeing the effect of a medicine - tablet, injection, inhaler - or another treatment (e.g. exercises) or evaluating the impact of technologies (like smartwatches, falls alarm, video calls, or 'robots'). It might not need any involvement from the person, e.g. using data collected during routine care.

The research process

Although every research study is different, most will follow a similar process.

Understanding this process helps us to make sense of what research is. This section outlines the key features of planning and designing research, data collection, analysis, and sharing the findings.

Stage 1: Planning

To begin with, a researcher or a team of researchers will have an idea. This idea can come from their own experiences, suggested by others with relevant expertise, e.g. care home residents, their families, staff, or government, or it might lead on from research that has already been completed. Usually, this process will involve reading and reviewing existing evidence to check that the idea needs new research to be addressed. This is called a literature review. If the existing literature review suggests a knowledge gap, then a research question will be developed to inform a new study.

For example, a group of care homes in Lothian who meet regularly with researchers discussed how one care home's staff had benefitted from regular reflection and debriefing sessions. During these meetings, they discussed a resident who had died and shared memories of them. They also learned from palliative care specialists about what aspects of care they did well and what could be improved. During COVID-19,

these sessions were adapted for online use as part of a research project and rolled out to over 20 care homes.

An evaluation showed how this benefitted staff and highlighted the challenges of taking part.



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Stage 2: Design

The research question is developed into a study during the design stage and carried out by the research team. They think about how the question should be answered and how to gather data to answer the research question. Data can be numbers (quantitative research), words (qualitative research), or a mix of both (mixed methods research). When it has been decided what type(s) of data is needed, there are many practical and theoretical things to consider about how the data will be collected and what will be done with it.

A detailed study plan will then be developed, which is called a protocol. It should outline why, where and how (these aspects are the methods) a study will be carried out. Parts or all of a protocol will then be shared with organisations that fund research so the study can go ahead. Researchers also need the plan of their study to be reviewed by an ethics committee (e.g. university ethics panels, NHS ethics committees). Ethics reviews check that any risks to participants are kept to a minimum, and identified risks have management plans so that if/when they arise, the participants are attended to in the safest way possible.

Stage 3: Data collection

Data can be collected in lots of ways depending on the research question and the methods chosen by the researcher(s). This is the first stage where care home staff and residents who are willing and able to participate will be involved. Some people see adverts in newspapers or on social media or will be given a leaflet by a professional who knows about the study. Care homes that receive the ENRICH Scotland newsletter can access research opportunities this way.



Anyone interested in potentially participating is then given an overview of the study called a Participant Information Sheet. This should explain:

- The purpose of the study
- How participants will be involved
- The time commitment expected of them
- How their data will be managed
- Their right to withdraw

This information needs to be in plain language to help them decide if they want to and are able to participate. If, after finding out more about the study, a person thinks they want to participate, their eligibility will be reviewed by a research team member. Each person must meet a list of requirements called the 'inclusion criteria'. There should also be another list of why they might not be suitable to take part, called the 'exclusion criteria'. If a person meets all the requirements, none of the exclusions and still wants to participate, they will be asked to read and sign a consent form. People who lack capacity cannot legally consent to participation, but there are procedures that can be followed to allow them to participate. Under the Adults with Incapacity (Scotland) Act 2000, a relative or legal representative can be asked to provide consent for someone who doesn't have capacity, known as 'proxy consent'. For more information about research participation for people with dementia, read Alzheimer Scotland's *Volunteering for research* information sheet.

Participants can withdraw at any time from a study for any reason. They do not need to say why they want to withdraw but they might be asked. This is to help researchers understand if there was anything that they could have done to better support participants, and can help when planning future research studies.

When a person has consented to participate, researchers will start to collect data. This is a significant milestone in a study and is always very exciting for researchers. If a drug, treatment or service is being tested, participants will start to receive that at this stage, and the researchers will closely monitor them. If the study is interested in understanding the experiences or opinions of participants, researchers will gather data through methods like focus groups or interviews, or they might ask participants to complete diaries. An interview or focus group will typically last from between thirty minutes to two hours, depending on the subject. It's important to think about alternative methods of communication. More traditional methods of gathering data such as Interviews and focus groups won't suit everyone. Art therapies and activities, such as dance, music and drama, can also be used to gather data. These types of approaches have proved effective for people with dementia. Participation can vary from a one-off meeting with a researcher or can last months, mainly if a medication or treatment is being tested. Researchers might ask participants to complete surveys or questionnaires which can be on paper or online. Completing them is usually quite a quick process and can take anywhere from a few minutes to thirty minutes. An estimate will usually be included in the Participant Information Sheet.

Data collection continues for the duration of the treatment, until a participant drops out or until a target has been reached. There is usually a timeframe within which this should be completed, but sometimes researchers need to review this.

Stage 4: Data analysis

Data analysis is the process of identifying patterns in data to create meaning. The research team carries out this stage. For quantitative research that collects numbers as data, this stage will tell them if the drug, treatment or service that their research question is based on is likely effective (or not). For qualitative research that uses interviews, focus groups, or creative activities like writing or photography, researchers will review the participants' words or creations to identify themes to help them answer their research questions. In all types of studies, data is anonymised to protect the participants' identities. Depending on the type of data and how it was collected, there will be recommended ways to carry out an analysis. Some studies wait until all the data required has been gathered to start analysing it, whereas others analyse as it is collected. Some researchers need computers and programmes to help with managing, storing and analysing data.



Stage 5: Sharing the findings

When the data that has been collected has been analysed, researchers will write up their findings. This involves comparing what they have learned with existing research and making recommendations for future practice and research. Study participants should have early access to findings and might be invited to events where the findings are presented and/or received in a newsletter. Sharing findings with participants before publishing them is thought to improve the results' trustworthiness by checking that participants feel that the study's findings have accurately reflected their views. For findings from research to benefit wider society, it is important that they are shared with the public in an accessible way. Findings might be included in a report for the government, the organisation that funded the research, or published in a journal. They might also be presented at events like conferences or public meetings and through blogs or social media. If the researcher is a university student, they will also share their findings in their dissertation or thesis.

Examples of care home research

- UCAIRE: Infection risk in care homes during COVID-19
- DACHA: Developing resources and minimum data set for care homes' adoption & use
- LADDeR: Landscape assessment of data and digital readiness of Scottish Care Homes

Reflective prompts

- What support and resources do you think would be needed to enable research participation in the care home where you work?
- Can you think of a question about the care home you work in that could be answered through research?
- Can you think of how you could be involved in the research process?
 What stage are you most interested in?
- Can you help others (colleagues, residents, family members) be involved, and how would you do this?
- Can you think of any benefits to enabling people to be involved in research in your context?

Section 2 Benefits, challenges & practicalities



Research has often been carried out in controlled environments with people with a narrow set of characteristics, e.g. excluding people over the age 80 or with multiple health conditions. This was thought to produce the most reliable results. We know, however, that findings produced from this type of research may not be relevant for everyone, especially for people who live in care homes. People who live in care homes often have multiple health conditions that need treatment and might be on numerous medications, which they want to be sure they need and will work for them. Researchers must consider this when recruiting.

Care home research can be complicated. Care homes (and any homely environment) can be lively and unpredictable, with a high staff turnover. The health and wellbeing of people who live in care homes can also be changeable. The COVID-19 pandemic has exacerbated these existing issues. Unfortunately, these circumstances can prevent researchers from designing studies for care homes. And it is not just researchers who can find care homes a challenging place to carry out research. Sometimes there is an element of mystery about what researchers do and what is involved. Consequently, research participation or involvement will understandably not be a priority for care home staff working in busy environments – caring for residents through established processes is sufficient.



However, participating in research creates opportunities for staff and residents, including:

- Developing new knowledge and skills from professionals that would otherwise not be available
- Sharing experiences and opinions that will inform future changes to practice
- Improving the standard of care and quality of life for residents
- Influencing future practice and care

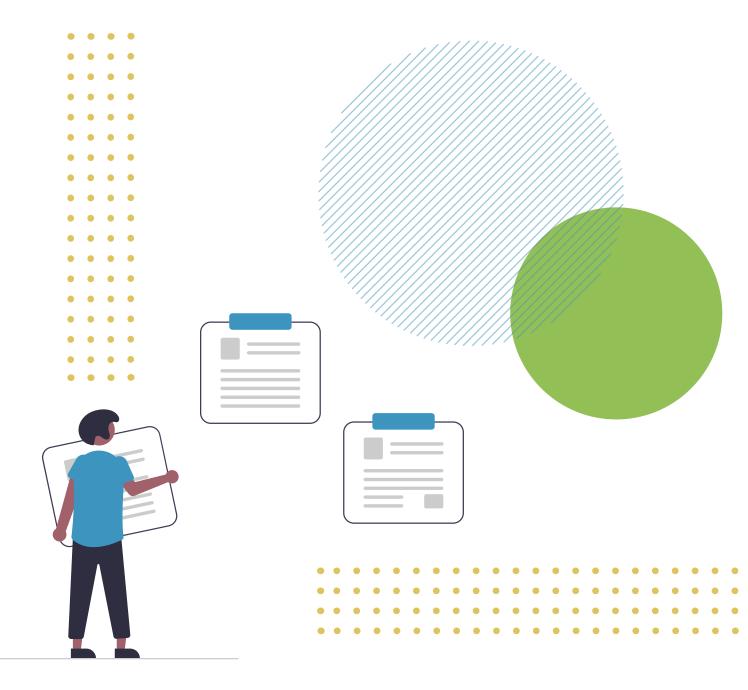
The increased attention given to care homes because of the COVID-19 pandemic evidenced a general lack of understanding of living and working in care homes. It also highlighted that the policies and guidelines developed for care home staff must consider that a care home is first and foremost a home. Addressing these oversights has created opportunities for far more research. Ultimately, the benefits of research to care home staff, residents and their families outweigh the challenges. Nevertheless, the challenges should not be overlooked or viewed as easy to overcome. For these reasons, the Enabling Research in Care Homes (ENRICH) research network was developed.

In 2012, a small team of researchers set up ENRICH to increase care home staff and residents' opportunities for research. The team successfully increased research participation in care homes in England and the associated benefits. A similar approach has now been rolled out across Scotland. ENRICH Scotland is a team of professionals from nursing, medicine, psychology, social work and occupational therapy, with experience that can help care homes with research participation. They are available to share information about research opportunities, answer any questions about the studies or set up meetings between care home staff, residents or families and researchers. ENRICH Scotland works closely with partners including the Care Inspectorate, Scottish Care, Scottish Social Services Council, Iriss and the Health and Social Care Alliance Scotland, to ensure that research developed for Scottish care homes understands social care priorities and policy.

¹ Bunn F, Goodman C, Corazzini K, Sharpe R, Handley M, Lynch J, Gordon A. L. (2020). Setting Priorities to Inform Assessment of Care Homes' Readiness to Participate in Healthcare Innovation: A Systematic Mapping Review and Consensus Process. International Journal of Environmental Research and Public Health, 17(3), 987. Retrieved from https://www.mdpi.com/1660-4601/17/3/987

Reflective prompts

- Thinking about your care home, what do you think are the benefits of participating in research? What enablers or strengths are already in place?
- What challenges are there to doing research in your care home? How could these be addressed?





Section 3 Interview 1: researcher

Maria Drummond spoke with Julie Eshleman about her experiences carrying out research in care homes. Julie is a behavioural analyst and a PhD student at the University of Stirling. She has been involved in various projects that integrate technology into care homes. For her PhD, she is leading research that explores the user experience of technology in care homes.

Maria: Tell me a bit about your research.

Julie: A lot of research has been done on telecare and telehealth and ways that technology can be used by the workforce to deliver care better or differently or more efficiently. When I'm talking about technology, it's things like general smarthome tech, Alexa, voice-activated assistance, smartphones and tablets, laptops, smart TVs, things that make someone's living environment more enjoyable and more accessible and gives people more options for ways that they can manage their own time and space. But there hasn't been a lot of research on how people who live in care homes are experiencing this technology.

Maria: How do you prepare for entering a care home to carry out research?

Julie: Usually, I start with pre-research work with staff: 'What do you feel about this? What's the most important thing about this to you and how do you see this?' We start with careful messaging and working with staff, and building rapport. We try to start getting some staff buy-in and get people thinking the way we're thinking. And then using those people to seed the rest of the staff and start demonstrating the small changes and why we're doing those things that way so that we can lay the groundwork for the bigger things that we're going to ask them to do. Like incorporate new kinds of technology or

support people to do something very differently than they have before, but it always does have to start with kind of getting a lay of the land.

Maria: Is there any time when you've done groundwork where you and your team have learned from the care home and have taken that back to your team to say we need to adjust our approach?

Julie: Definitely. That happens a lot. We don't tend to go in anymore with a really clear aim. This is exactly what we're going to do to get there, and we're starting here and off we go ticking down this list. We usually enter into it in a very exploratory way, like we think we have this kit, we have these technologies. We think everybody might want them, but we don't really know. Let's figure out where we can start.

Maria: At what points in projects do you feedback to the care homes involved?

Julie: Generally, it's all along the way, especially at our main project site. The delivery team is on-site, so they report to the service manager every day. They're very integrated into the care homes, so they get progress really often. And also, we're very mindful of when the care home is being evaluated. We try to provide them with lots and lots of evidence for them to use when they're being evaluated so that they can highlight the really important aspects of technology that are going to be pertinent to their rating.

Maria: How convinced are you that research can be an important part of a care home?

Julie: I am extremely convinced. I have seen research be pretty career shifting for people to just hear me ask questions about service users' experiences. If I'm doing some interviews to just get some user experience from residents in a service and they have any kind of communication difficulties or they just want a care worker there to just kind of support them and listen and help make them feel comfortable when they're talking to me. I've had care workers who are like, 'I didn't know that was important to you. I didn't know that you felt that way'. There have been some very big revelations on the part of staff just hearing about people's experiences. The act of getting people to share their experiences and being really inquisitive and just curious and wanting to hear and listen has changed the way a lot of care workers provide care and the way they interact with the people that they're supporting. Which I think is really important, because do I need them to be researchers? Well, no, but do I think that they're learning a lot, just having

research happening in their setting? Yeah, I do. I think that they learn a lot, and they have pulled a lot away from that and changed some of their processes completely independently without our support. But just saying, you know, after we saw you guys doing those things, we realised that this is really not working and so we went to our manager, and we asked to do it this way, and she said that's fine. So, you know, just seeing it going on around them has, I think, inspired them to innovate a little bit differently.

Maria: So, if there's lots of investment and there's lots of support, what happens when that comes to an end?

Julie: It depends on the project, but generally, we haven't had any projects where we haven't spent the last third of the project on sustainability. So building local capacity, finding ongoing investment and funding, maintaining new kit, learning about new things and supporting residents to use new stuff. So, we do focus a lot on sustainability and making sure that we don't leave a site until they are equipped to carry it on to the extent that they want to. We try to follow an "I do it, we do it, you do it" project model. We start with our project team doing most of the work (the "I do it" phase). Then we invite on-site staff to start doing some of the project activities (installation, training, maintenance and support) alongside us, (the "we do it together" phase). Then we start to empower the staff who have come alongside us to take over a bit while we are still there to support, troubleshoot, see how it goes... (the "you do it" phase). That has been a pretty successful model because it builds staff confidence to keep supporting the technology even in our absence, but while we are still there to help if things go wrong.

Maria: What advice would you give to care homes that have never participated in research before?

Julie: I think that research gives you a real opportunity to innovate with a lot of support. And generally, if there is an investment that has been agreed for a site, that's about the most support they are ever going to get to make a change. So, if they want to innovate and they want to make a change and haven't previously had the resources or support, then engaging in research is a really cool way to get to do that without having to rely on your own resources entirely.

Reflective prompts

- What resonated with you most from what Julie said about care home research?
- Was there anything that Julie said that you feel doesn't apply to your work area? And if not, why not?
- The following quotes are from researchers involved in care home research.

 They highlight some of the barriers and enablers:

"A really helpful thing is the care home manager being onboard and making sure their staff are informed." (Researcher)

"I feel the one thing we always walk away from is if the individual care home manager doesn't want to take part because there's just no point." (Researcher)

"It helps if the care home manager introduces you, as you feel like you have validity in being there." (Researcher)

"That's why I wanted to be involved in the research because I know we don't always get it right." (Care home manager)

• The quotes illustrate the importance of the care home manager's role - how might you help ensure their support, and what are some of the challenges to this?





Section 4 Interview 2: care home staff member

Maria Drummond met with Gary Butchart, the manager of Storyville residential care home in Kirriemuir. Below is an overview of their discussion where Gary reflected on how he feels about the prospect of the care home participating in research in the future.

Maria: Why do you think research in care homes is important?

Gary: There's always so much going on in care homes, not just with COVID, but care homes in general. So, it's great that researchers are taking an interest and looking at care homes, not negatively either, but positively asking 'what can we do better?'. Everyone working in the care home industry is looking for ways to make the care and the environment better. Anything that can help, we're all for.

Maria: What areas of care home care and staffing do you think could be explored through research?

Gary: I think the main area at the moment is staff wellbeing and mental health. We've come through so much, and we're going to go through a lot.

Maria: What kind of support or training do you think would be needed for staff and residents to participate in research?

Gary: I think time needs to be spent explaining the goal, what's involved. It can't be 'here's the tools, now get on with it'. We also need to have support the whole way through and regular communication. Yes, this communication could be by email, but that can be a bit impersonal; regular face-to-face would be good to get the residents involved as well; it's important to find out their thoughts on what would

be happening too. There might be times when residents and staff are tired or busy, or when there are things happening in the home, and they can't participate.

Maria: It sounds like, even when there are challenges in a home, where the priorities are providing care and solving problems, teams that are embedded in care homes can learn just by being around, lots of opportunities for shared learning. When we think about all the different types of approaches to research, are there any specific ones that you think are more or less suitable to care homes?

Gary: Other than a drug trial, which I think I would be most cautious about, really, I think we would be open to anything that would benefit residents' wellbeing.

Maria: There are so many more people who now want to do research in care homes. Does it matter to you who is involved in the research team?

Gary: No, so long as the care home and the research team have a shared goal. It's staff input that's vital because they always try to go over and above what's expected of them. So, as long as there's a shared goal and regular communication, I don't think there'd be any problems.

Reflective prompts

- Do you agree with Gary that there is a need for research that focuses on staff wellbeing and mental health?
- Are there other topics you think need to have a research focus on?

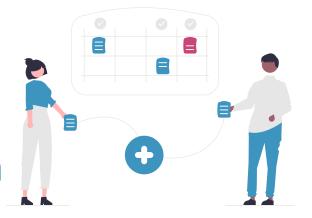
The following quotes have been taken from researchers about conducting research in care homes:

"People can be hostile, but they are just being defensive and are just worrying about their job safety."

"Communication with the staff is the most important thing in terms of getting things done."

- How might you address staff concerns about research in care homes?
- Thinking about communication in your context, what already works well, and what improvements do you think need to happen to support care home research?

Section 5 Partners in research



Increasingly, there is an understanding that research should be done with those involved, instead of, to them. This now typically involves volunteers with lived experiences of the topics of interest who are available to act as expert advisors to the research teams.

Involving people with lived experience is a great opportunity for researchers to check that the question they are asking is relevant, the data they want to collect is appropriate, and if there are any practical aspects of the data collection process that they might not have thought of.

Joining advisory groups can also be beneficial for those involved. People with lived experience can become integrated into projects, form new relationships and get involved with key decision-making. They can use their expertise to improve the quality of research produced so those most affected will potentially have more to gain. For example, if senior carers are to be interviewed about mealtimes in a frail and elderly unit of a care home, volunteers can suggest if the interviews should be conducted before, during or after a shift.

There are various descriptions of this role, including Patient and Public Involvement (PPI), Partners in Research and co-production. People living with dementia and neuro progressive conditions said they would rather be described as 'Partners in Research', so this is the term used by ENRICH Scotland.



Reflective prompts

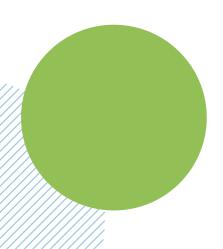
- If your care home has groups that meet to discuss various issues such as a relative's group – do you think the topic of research could be introduced to that group?
- If your care home does not have any groups which meet, do you think you would be able to start one up and what help would you need to do this?
- The following quotes are from care home residents and their families, representing different views on taking part in research:

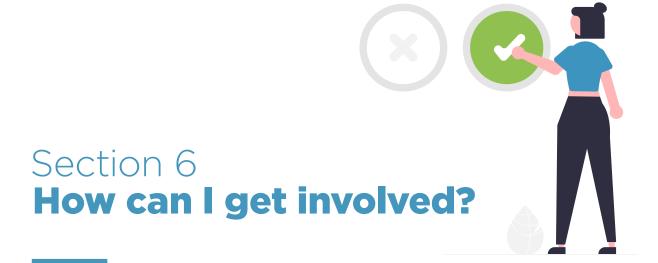
"I'm no' very clever right enough." (Resident when asked if they would be willing to take part in other research)

"I think it's extremely important. If one is in a place like this, one must contribute oneself. You can't just sit and wait for things to be done for you. You've got to use your own ideas and you've got to keep yourself alive and awake and contribute to anything which is offered you." (Resident)

"I'd like mum to join in more but she doesn't feel she can so... She's quite isolated really. Aren't you, mum? You're quite isolated because you stay in your room." (Relative)

How might you encourage and support residents to take part in research?
 What challenges might you encounter, and how might you address these?
 What strengths are you be able to build on?





Working in a care home is a fantastic opportunity to learn skills, meet people from different backgrounds and do a job that adds so much value to society. This wealth of knowledge and experience can be shared through research involvement and participation. If you are interested in participating in research or supporting the care home that you work in to become active in research, then ENRICH Scotland can support you to do this.

Firstly, the manager of the care home that you work in can receive our newsletter, which details current research opportunities. Care homes that receive the newsletter also receive a certificate acknowledging that they are 'Research Ready'. This certificate is endorsed by the Care Inspectorate and can be displayed to show that the care home is interested in improving the quality of care through research. To start receiving our newsletter and receive a Research Ready certificate, please email: tay.enrichscotland@nhs.scot.

We are also always looking for Partners in Research volunteers. An example of an area that care home staff could volunteer to help ENRICH Scotland with is the development of a Research Champion. A Research Champion will have the opportunity to gain skills and experience from care home researchers, but we need care home staff to help us work up this idea.

ENRICH Scotland also supports a group of care homes called the **Care Home Innovation Partnership**. This is a care home-led group in Lothian that identifies areas they think could be improved; it develops their ideas with researchers through quality improvement methods. The group are seeking care homes to join, and ENRICH Scotland would like to replicate this model in other areas of Scotland.

For more information, get in touch with **ENRICH Scotland**.

