Toolkit for Increasing the Participation of Rural and Coastal Communities in Health and Social Care Research

Authors and Contributors

Authors

Dr Hayden Bird
Post-Doctoral Research Associate, Lincoln International Institute for Rural Health, University of Lincoln

Professor Mark Gussy
Global Professor in Rural Health and Social Care and Director of the Lincoln International Institute for Rural Health, University of Lincoln

Dr David Nelson
Research Fellow in Rural Health and Care, Lincoln International Institute for Rural Health, University of Lincoln

Ava Harding-Bell
Community Researcher and Expert by Experience, Lincoln International Institute for Rural Health, University of Lincoln and Chair, Swinsehead Patient Participation Group

Professor Azhar Farooqi, OBE
General Practitioner and Honorary Professor, College of Life Sciences, University of Leicester, Chair Leicester City CCG

Dr Ffion Curtis
Lecturer in Evidence Synthesis, Liverpool Reviews and Implementation Group (LRiG) University of Liverpool

Contributors

Dr Helene Markham-Jones
Post-Doctoral Research Associate, Lincoln International Institute for Rural Health, University of Lincoln

Dr Maxime Inghels
Research Fellow, Lincoln International Institute for Rural Health, University of Lincoln

Dr Paul Mee
Senior Research Fellow, Lincoln International Institute for Rural Health, University of Lincoln

Dr Samuel Cooke
Research Fellow, Lincoln International Institute for Rural Health, University of Lincoln

Professor Mo Ray
Professor of Health and Social Care, Director of the Healthy Ageing Research Group, University of Lincoln and Clinical Research Network (East Midlands) Speciality Lead for Social Care

Thomas George
Research Assistant and Lecturer, School of Health and Social Care, University of Lincoln

Amy Thomas
Head of Charity, Lincolnshire Rural Support Network lrsn.co.uk

Vicky Thompson
Chief Executive, Every-one, every-one.org.uk

Colin Hopkirk
Business Development Lead, Every-one, every-one.org.uk

Ann and Richard Avison
Lincs Digital

Elected members and staff
South and East Lincolnshire Council's Partnership

Elected members and staff
Lincolnshire County Council

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Abbreviations and glossary

CMO Chief Medical Officer

CPD Continuing Professional Development

CRN Clinical Research Network

ELDC East Lindsey District Council

HARG Healthy Ageing Research Group

ICS Integrated Care System

LA Local Authority

LCC Lincolnshire County Council

LIIRH Lincoln International Institute for Rural Health

LRSN Lincolnshire Rural Support Network

LWC Living With Cancer

NHS National Health Service

NIHR National Institute for Health and Care Research

PCN Primary Care Network

PPG Patient Participation Group

PPIE Patient and Public Involvement and Engagement

RUTH Residents Using Temporary Housing

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Foreword

The majority of UK landmass is classified as rural or coastal and is home to approximately 20% of the total population. These places are also home to significant historic, cultural, and natural national assets including health-supporting blue and green spaces. Paradoxically, alongside this amazing and precious social capital are many rural and coastal communities which are disproportionately vulnerable to deprivation, economic shock, climate change, higher disease burdens, and inequalities in health and wellbeing outcomes. Rural populations, small seaside towns and sparse settings are generally less ethnically diverse and have higher proportions of older people. There is a general trend for net migration from predominantly urban areas to predominantly rural areas with increased migration noted since 2008/09. Access to health services and hospitals is more challenging in rural areas with reduced services, poor transport infrastructure, and consequently greater cost incurred by residents. Although the COVID-19 pandemic reaffirmed the importance of access to timely health, care, and wellbeing services, the impact on access to services and wider social determinants of poorer health remains omnipresent.

Despite these challenges rural people are underrepresented in health and social care research. This can impact the quality of the research by reducing the generalisability of findings and/or by limiting the 'strength' of the research methods being used by researchers. The result of this is twofold. Firstly, there is limited understanding of health and social care as it operates in rural settings and, secondly, research conclusions give an incomplete picture of the entire population. It is also unfair, from an equity perspective, that groups traditionally underserved by research continue to be excluded from studies because of where they live.

The reasons for this ongoing exclusion are multifaceted. The literature tells us it is likely due to difficulties with travel time and/or communication technology, comparatively higher costs of involving rural and distanced residents, cultural aversions, and values and concerns about privacy in small communities. There are likely other more nuanced barriers, but potentially more effective ways of including residents of isolated rural and coastal communities in health and social care that can only be known by engaging directly with them. In this respect, inequities experienced in accessing services are somewhat mirrored in the challenges of engaging these communities in research. There are practical and emotional implications for both those undertaking research and those who are included as participants.

This toolkit is offered as a resource for those interested in developing health and social care research that is maximally inclusive of all people regardless of where they live.

Mark Gussy
Global Professor in Rural Health and Social Care and
Director of the Lincoln International Institute for Rural Health,
University of Lincoln

Toolkit Overview

This toolkit has been developed under the leadership and collaboration of a multidisciplinary group of researchers, stakeholders, and residents from a variety of backgrounds. It includes those who live, work, volunteer and undertake health and care research with rural and coastal communities. It has been created from undertaking a rapid evidence review to identify the key barriers to, and enablers of, increasing participation in health and care research with rural and coastal communities. These findings were tested out in focus groups and semi-structured interviews. During the later stages of data collection, a project workshop was facilitated which involved diverse participants who had already taken part in focus groups or interviews. This enabled findings from existing research and the qualitative data to be challenged, validated, and refined. This process prioritised findings that were subsequently translated into a shortlist of 7 Core Guidelines and each guideline has identified dimensions to inform researchers. They can be used as part of the full toolkit or as a standalone checklist of considerations and is included at the end of the toolkit. Some align to specific phases in the research process, whereas others represent crosscutting principles for enhancing engagement over the life course of individual and multiple studies.

7 Core Guidelines structure the different sections of the Toolkit. They do not convey a chronology for 'conducting' research as different components can intersect at different times. They are intended for use at different stages of research and evaluation, including: before and during public/stakeholder engagement; to inform collaborative research design; and shape studies formatively as they develop in real time. Finally, they provide a summative tool to reflect on completed studies, to promote learning that can be applied to future engagement, funding bids, Continuing Professional Development, and the design of future studies.

The 7 Core Guidelines are:

Core Guideline 1: Developing strategies for involving rural and coastal communities in health and care research

Core Guideline 2: Lessons from the looking glass? Research engagement mirroring the effective delivery of health and care services

Core Guideline 3: Identifying and working with 'underserved communities' to understand their needs, behaviours and preferences

Core Guideline 4: The value of positive and flexible approaches to communication in reaching stakeholders

Core Guideline 5: Promoting the relevance of health and care research

Core Guideline 6: Building flexibility into your research approach

Core Guideline 7: The symbolic resonance of research in rural and coastal communities: Preparing for, and continuing with, 'emotional labour'

Each section for the 7 Guidelines adopts a common format with the Guideline title being accompanied by a short sentence summary capturing its essence. Guideline dimensions provide a detailed breakdown of 'top tips' that you may find useful. Each section is accompanied by 'real world' quotations from our fieldwork, and a case study to illuminate interesting lessons for best practice.

Rapid Evidence Review

What we already know about the challenges for engaging rural and coastal communities in health and care research

Barriers to participation and retention of respondents in health and social care studies within rural and coastal areas can be framed in three overlapping domains: **the participant; the researcher; and the community/institution.**

Barriers within the 'participant domain' included: lack of awareness or interest in research (Sethi et al, 2021; Geana et al., 2017; Pathak et al., 2019; Coyne et al., 2004) as well as potential respondents' health condition(s) being attributed to their under-involvement (Beattie et al., 2020; Burns et al., 2008; Coyne et al., 2004; Sabesan et al., 2011; Sethi et al., 2017). Infrastructural issues, such as lack of transport and access to health services and study sites can be exacerbated for these populations (Beattie et al., 2020; Coyne et al., 2004). Burns et al (2008) noted older women living in rural areas who had limited mobility often experienced difficulties travelling to research sites due to lack available public transport.

Barriers within the 'researcher domain' included: difficulties linked to imprecise measurements of 'rurality'; excessive administrative and time burdens incurred through overly complex research protocols and distrust of researchers and the research process (Afifi et al., 2022; Geana et al., 2017; Loftin et al., 2005; Pathak et al., 2019; Sabesan et al., 2011; Sommer et al., 2018; Sutherland & Fantasia, 2012; Virani et al., 2011). Regarding measurements of rurality, a few studies in USA noted that area-based definitions of rurality, such as a 'county', may not be sensitive enough to capture data on rural populations (Afifi et al., 2022; Pathak et al., 2019). Loftin et al (2005) reported that members of rural communities may perceive researchers as 'outsiders' even when they belong to the same ethnicity as they have a different level of education and do not have a long association with the community. Other studies pointed to concerns over lack of confidentiality (Sutherland & Fantasia, 2012) and negative perceptions of the research process (Geana et al., 2017). The Chief Medical Officer's 2021 Report on Health in Coastal Communities highlighted further complexity in defining coastal and experiences of these communities can be markedly different to nearby rural communities. Lack of funder recognition about these issues can limit researchers' abilities to develop and implement health and social care projects, and therefore improve peoples' wellbeing in these areas.

Findings within the community/institution domain indicated that recruitment of respondents in rural areas were mired by challenges associated with incorporating healthcare providers into recruitment (Beattie et al., 2020; Coyne et al., 2004; Geana et al., 2017; Loftin et al., 2005; Sabesan et al., 2011; Shebl et al., 2009; Sutherland & Fantasia, 2012; Vanderpool et al., 2011), poor infrastructure in rural areas (Leach et al., 2011; Loftin et al., 2005; Pathak et al., 2019; Sethi et al., 2021; Shebl et al., 2009; Sommer et al., 2018; Sutherland & Fantasia, 2012; Vanderpool et al., 2011; Virani et al., 2011) and difficulties in communication (Loftin et al., 2005; Shebl et al., 2009). A study comparing patients awareness of clinical trials for cancer by area of residence found that participants living in rural areas were less likely to view leaflets on clinical trials in the waiting areas of their clinics or discuss their eligibility to participate in comparison to their urban counterparts (Geana et al., 2017). Other studies found that patients were reluctant to be enrolled in a clinical trial if their physician either actively discouraged it (Virani et al., 2011) or were unsupportive (Vanderpool et al., 2011). Potential respondents living in rural areas often had to account for time spent travelling, cost of transport, finding accommodation near clinic sites and the possibility of reduced earnings due to the demands of the study (Pathak et al., 2019). An additional barrier was that participants from rural areas were keen for a family member to accompany them at the research site (Sabesan et al., 2011; Virani et al., 2011), which would be difficult to coordinate if the study site is far from where the participant resides.

What we know about the enablers for engaging rural and coastal communities in health and care research

Researchers employed a wide range of strategies to address barriers within each conceptual domain. They often used a combination of these techniques to spark communities' interest in their project and increase convenience of research. Many of these strategies tackled one or more of the conceptual domains simultaneously. These strategies were categorised as a) appropriate and flexible methodology; b) incorporating communication technologies; c) educating and informing; d) interpersonal strategies; e) drawing on trusted community networks and f) building and maintaining community partnerships.

Core Guideline 1: Developing strategies for involving rural and coastal communities in health and care research

The terms rural and coastal are commonly used as overarching labels. Planning, engaging, and researching with people in these communities requires strategies that go beyond homogeneity and work with the complexities of place, communities and populations to develop shared understanding of these diversities.

Guideline Dimensions

- Objectively defining rural and coastal communities by population size and/or number of households can be contextually limiting – especially when seeking community engagement and collaboration.
- Subjective identities are key. Have you thought about how people may define themselves and the issues that matter most to them?
- Identify formal gatekeepers (such as health professionals, local authorities and community development representatives) and informal gatekeepers (such as residents).
- Complexities of 'place' can include a range of issues. Examples include demographic make-up, environment, multiple deprivation, local economies, health and care needs, and gaps in provision, alongside community services and assets.
- Patient and Public Involvement and Engagement includes networking, recruitment and retention of Community Researchers who should be costed into the project as research team members.
- Consider additional costs prior to research design and budget to support participation where practicalities prevent inclusion. This can include: travel provision; subsistence; and accommodation (for participants and researchers); as well as establishing when and where engagement and data collection take place.
- Participants should be paid for their time to replace loss of earnings. Above meeting costs, participants should be rewarded through inclusion in grant proposals and budgeting.
- Consider the implications for refining your sampling approach and size.

Case Study:
Research Ready Communities

Mo Ray, Jo Blackwell and Thomas George at the Healthy Ageing Research Group in the University of Lincoln have been funded by the National Institute of Health and Care Research (NIHR) Clinical Research Network in East Midlands as part of a national programme to work with areas considered underserved by research engagement. The team have been working with three community partner organisations in Lincolnshire (Darkside Rising Community Interest Company, and rural hubs at Hemingby and Alford) recruiting Community Champions. A Community Champion knows their community and develops research ideas through community meetings, discussions, and focus groups. They facilitate community conversations by reaching out to local people, including rural communities. Through these activities the challenges and opportunities for engagement in research are explored, focusing collaborative planning so it translates to community actions and outcomes. Findings from this work will shape future research and are being fed back to the NIHR with a view to continue to work with Champions in other parts of the region. Mo Ray has summarised the benefits of Research Ready Communities: *"The project has provided valuable opportunities to build relationships with local communities and, with the expertise and knowledge of community champions, to understand what citizens know and their attitudes towards research and research participation. Through the research ready communities project, we have been able to support participation in research as well as the active participation of champions and citizens in research development. It is an absolute pleasure to be able to work with community champions and local communities and within a short space of time has had tangible benefits and outcomes for citizens, community champions and researchers."* A Champion from one of the Research Ready Communities outlined key benefits of the collaboration, as being *"a great opportunity to connect in rural areas. A chance to enhance community while contributing to a meaningful project"*.

Core Guideline 2: Lessons from the looking glass? Research engagement mirroring the effective delivery of health and care services

Compared to urban areas, rural and coastal communities experience significant factors that impact on their engagement in health and care services. Lessons from tailored approaches to delivery can be mirrored in, and applied to, research studies to increase participation.

Guideline Dimensions

- Understanding rural and coastal inequities relating to engaging with health and care services can support effective collaboration, research design, participant recruitment, data collection and dissemination.
- Collaborative shaping and delivery of health and care services and research studies require thinking which is outside existing approaches – implementation may require thinking about culture-change for policy makers, research governance and funders.
- Ongoing awareness of community assets and strengths can shape services and research opportunities.
- Identifying perspectives on gaps in, and barriers to, quality service provision are instrumental in building and demonstrating an understanding of lived experiences within communities, which add to researchers' credibility .
- Centralisation is a challenge requiring researcher time. Locating key services, such as cardiac care, in highly urban settings can influence perceptions of need/demand and the rest of the county/region. Research activity can replicate this model of delivery – leading to gaps in participation and evidence.
- Adherence to a deficit's perspective relating to services and problem-oriented research can be myopic. Researchers should understand the health and wellbeing benefits of living in rural and coastal places.

> "As far as the Lincoln University goes we have a medical school. We have a school of health and social care, we have paramedic, science. We have nursing. We have social work. We have all sorts. I'm not so much interested in Lincoln becoming a University Hospital, but I am interested in Grantham and Boston and other places, not winding up with everything at Lincoln."
>
> **PPG stakeholder**

> "Some of those issues that are endemic in terms of equity of access to services, applies equally to research, so things like the fact that different areas might require different approaches, so that whole equity issue,… we know there are workforce issues in coastal areas nationally and equally Lincolnshire, I think it's something like 8% less nurses per person in coastal areas than the rest of the country… all of those things are issues for Lincolnshire and for coastal parts of Lincolnshire and it's no different for research…Different approaches are required in different types of communities and it's not just coastal, it's rural and market towns. It's urban areas. It's in urban industrial areas."
>
> **Local Authority Public Health Stakeholder**

> "I mean if you're talking about Caravan parks. How do you reach people to talk to them about a healthcare research study? We can't go banging on caravan doors. It's I mean, a part of it is our team being out there in the community and visible. But how did you do that on a consistent level? So, for me there is an element of this goes hand in hand with service provision in these sorts of areas as well."
>
> **Community Development Stakeholder, Public Sector**

Case Study:
Aligning research and service delivery with place – A Campus for Future Living

The Campus for Future Living proposal attracted £8.6 million of funding through the Town's Fund, part of the UK Government's plans for 'levelling up' communities by providing them with the tools to make their places better. The Campus for Future Living is a development on Stanley Avenue in Mablethorpe, Lincolnshire. It is situated in a group of coastal communities with some of the highest levels of multiple deprivation in the country. The development offers significant potential to improve the health and wellbeing for residents with implications for the Lincolnshire coastline and other coastal communities in England (further validated by the 2021 Chief Medical Officer's Annual Report on Health in Coastal Communities). For the first time, the vision places Mablethorpe at the forefront of medical innovation, training, research, and development. The main Campus building (the Centre for Future Living) will include two large consultation rooms, seminar and teaching rooms, an event space including a coffee hub, a pathology laboratory and additional laboratory space. The Campus site also includes an accommodation block, a children's play area, and a 35-space car park including eight disabled bays and electric vehicle charging points. It also incorporates the existing Marisco Medical Practice (General Practice). The Campus for Future Living is also contextually significant in addressing challenges to recruiting, retaining, and developing a number of professions in coastal and rural areas. The accommodation will enable people from urban areas to undertake CPD in rural and coastal health and care, whilst also engaging local people as users of the resource that will enhance awareness and popularity of vocational pathways in health and care. Speaking of the development Councillor William Gray from the South and East Lincolnshire Councils Partnership said that *"through the backing of the Government through the Town Deal, we are enabling millions of pounds to be invested in Mablethorpe to help improve the lives of residents, bring them new health opportunities, and attract inward investment to the Lincolnshire coast. The benefits will be long lasting for our communities"*.

Core Guideline 3: Identifying and working with 'underserved communities' to understand their needs, behaviours and preferences

Rural and coastal communities require understanding which goes beyond established appreciations of diversities and in close-knit communities there can be considerable variation in people's needs, their preferences for services and their behaviours. Concepts, such as rural proofing, should not homogenise these communities and their health and care issues.

Guideline Dimensions

- Feasibility and exploratory studies that accompany community engagement can provide a starting point for identifying and understanding complex and underserved communities.
- Underserved communities may include people who are both intentionally and unintentionally 'hidden'.
- Park homes and caravan sites are a key example of diverse people living in communities that have and/or go on to experience health and care issues.
- Communities can have shifting patterns of health and care needs, as well as demand for, and use of, services – including seasonality. Understanding these patterns can influence coproduction, design and timing of research.
- Underutilisation of rural/coastal residents as participants is not uniform. Some communities and specific sections of the population (including practitioners/professionals) may be subject to multiple evaluation activities and research fatigue.
- Mapping health and care issues can be problematic, but nonetheless useful building blocks for greater understanding and dialogue.

Case Study:
Mapping the Characteristics of Residents Using Temporary Housing (RUTH) on Lincolnshire's East Coast and their Exposure to Risk Factors for Type 2 Diabetes

Coastal communities are increasingly being identified as areas of growing risk for poor health and social outcomes. The Chief Medical Officer's (2021) Annual Report: Health in Coastal Communities highlights the unique health challenges faced by people who reside in coastal areas. Lincolnshire's coastal communities, particularly the towns of Mablethorpe and Skegness in the district of East Lindsey, are amongst the most deprived in the country. An ongoing study by the University of Lincoln is taking place on an important subgroup of Lincolnshire's coastal communities: those who are residents using 'temporary' housing (RUTH). Originally used to accommodate large numbers of holiday makers, including caravan and park homes, the quantity and quality of this accommodation has changed. There has been an increase in the number of people using these dwellings as their long-term residence. This has resulted in the emergence of what we might call long term RUTH. Findings from the project (Inghels, Nelson and Gussy, 2023) suggest that RUTH could be at higher risk for diabetes because of their characteristics (i.e., older population, poor reported health status and limited daily activities) and the place they live, mainly Lincolnshire's East Coast, which presents with elevated area-based risk indicators for diabetes. The implications of this research are important when considering a broader range of conditions and access to services. RUTH, combined with seasonality of the visitor economy and changing but 'hidden' population volumes are significant factors impacting on health and care services. A participant in the development of the toolkit described these challenges for the district: *"In East Lindsey there are 262 caravan sites, 37,000 static caravans. So that means for most of the year hundreds of thousands of people who are calling that coastal strip their home, just drawing on all the services on the coastal strip"* (Councillor).

Core Guideline 4: The value of positive and flexible approaches to communication in reaching stakeholders

The language involved in communicating research to rural and communities requires consideration, however 'communication' is more than using non-technical/ non-research focussed language. It can be verbal and non-verbal, potentially requiring multiple ways in which to convey research studies, study components and dissemination with people in rural and coastal communities. Ongoing dialogue is key.

Guideline Dimensions

- Communication presents opportunities as well as challenges for engagement, design and acceptance of research within rural and coastal communities.
- Infrastructure can be problematic – including connectivity and being 'off-grid'.
- Research should be mindful of engaging 'lay people'/residents in studies. Research proposals should demonstrate sensitivity to adopting different approaches for different sections of rural and coastal populations.
- Effective approaches to engagement include considering how, when, and where to promote studies and how to positively empower gatekeepers (be these official representatives or informally well-known points of contact).
- Ageing rural/coastal communities may require researchers to think about changing function and communication needs of the population. This can also include populations limited experience of prior evaluation and research activity.
- Strategies may include 'formal' communication through research materials, partnership promotion and 'informal' communication – networking in situ and taking advantage of existing, trusted, people, organisations and places.
- Collaboration on marketing and communications and dissemination outputs should follow NIHR's legacy of engaging lived experience over the study life course of pre-design to post-project completion.
- It is useful to assess if cultural awareness training is required.

Case Study:
Using engagement activities to increase participation in training and research: Digital Literacy in Coastal Areas

The Lincolnshire 'coastal strip' is made up of towns, such as Skegness and Mablethorpe, that offer a traditional English seaside holiday experience, with flat sandy beaches. The coast is also home to sparsely populated (and unpopulated) coastal landscapes. A number of these characterised by rolling dunes, foreshore grasslands, vast beaches and tidal flats recognised as some of the best wild beach landscapes in England, not only for visitor economy but also wildlife diversity. Across rural and coastal Lincolnshire there are areas that are 'off-grid', with challenges relating to broadband connectivity and speed, and mobile phone signal. The district of East Lindsey has a population where those aged 60 and over make up more than a third of the population a notably higher proportion compared to county and national levels. This includes people who have, or go on to experience, health and wellbeing issues in the later-life course. Skilled graduates and professionals often leave the area to pursue vocational pathways and career progression in urbanised areas, but a large number of 'retiree migrants' also move into the area and take advantage of more favourable house prices. Yet, similar to their settled 'local' peers they are underserved by a range of health and public services (such as transport, hospitals, and other services, which are continuing to diminish). With limited infrastructure and difficulties in accessing digital devices and skills development, digital poverty impacts on the ability of people to access digital/online services which support self-management of health and wellbeing, and engagement with health professionals. A recent project funded by NHS England has sought to test out an approach to address these issues through enhancing digital literacy in the Mablethorpe area. Taking a developmental approach, the project has drawn on Lincs Digital, an established grassroots provider, to upskill people as volunteer 'Digital Health Champions', who remotely support fellow residents.

The approach has been person-centred with project evaluation undertaken by the Lincoln International Institute for Rural Health at the University of Lincoln and economic development consultants Rose Regeneration. The project is providing gateway learning in the area to test-out interest in volunteer health and wellbeing roles and vocational pathways for people who are from the Mablethorpe area using the Campus for Future Living when it officially opens. The project drew on large and varied stakeholder engagement, including the local authority, members of medical and caring professions, as well as other community groups working in the area. A series of promotional events held prior to (and alongside) training and mentoring were key project enablers. One Digital Health Champion reflected on the support they had already provided to residents at their medical practice: *"The smiles, the thank you's, from the small gesture (such as booking an appointment), the positive experience of members of the community's feedback makes your contribution feel worthwhile and is so fulfilling."* The Digital Literacy Programme has created key advancements in best practice on engaging residents in skills development, promoting partnership approaches and enhancing CPD opportunities in coastal communities so they are attractive places for local people, as well as health and care professionals looking to gain experience in these settings.

Core Guideline 5: Promoting the relevance of health and care research

To increase participation of rural and coastal communities in research, demonstrable benefits including to the lived experience of residents, sections of the population, and 'place' are key in grounding research and community ownership. As indicated in Core Guideline 4, this may mean researchers being part of the communities they research, the networks they develop and adopting different styles.

Guideline Dimensions

- Research relevance involves communicating the benefits of research to the health and wellbeing of communities.
- The presence of research staff, teams and institutions in communities on an ongoing basis are integral to being applied.
- Sensitive approaches to people in rural and coastal communities are required – to recognise and constructively resist perceptions of researcher and Universities being viewed as physically and ideologically situated in urban ivory towers.
- Researchers can promote the role of studies in the setting of a wider relationship – providing their skills to support wider activities, research, and funding generation as part of 'buy in'.
- Outreach engagement is important – demonstrating the ability to coproduce research and services can be deeply symbolic for communities, organisations and individuals.
- Meaningful coproduction, takes place across the defining and development of research ideas, design and study inception and completion and knowledge sharing.
- Formats of information can include technical and 'easy read' formats - providing options for both can be a mechanism to empower access to outputs and promotional materials.

> "Let them know that you have, you know, looked into what they've said, because they've given you their time for nothing and if they don't hear nothing else from that, then they are not gonna help you the next time you ask. So, because I'm gonna think, well, you can't be bothered, why should I? So, it is very important to let them know what you did with that with research"
>
> **Resident Representative**

> "Another point that kind of occurs to me is about the reciprocal arrangements. So, I think few people have touched on this… What's the benefit for them? What do they get out of it? If we're always going saying we want this from you and we want that from that, eventually some people will say I'm not doing it anymore."
>
> **Post-Doctoral Research Fellow**

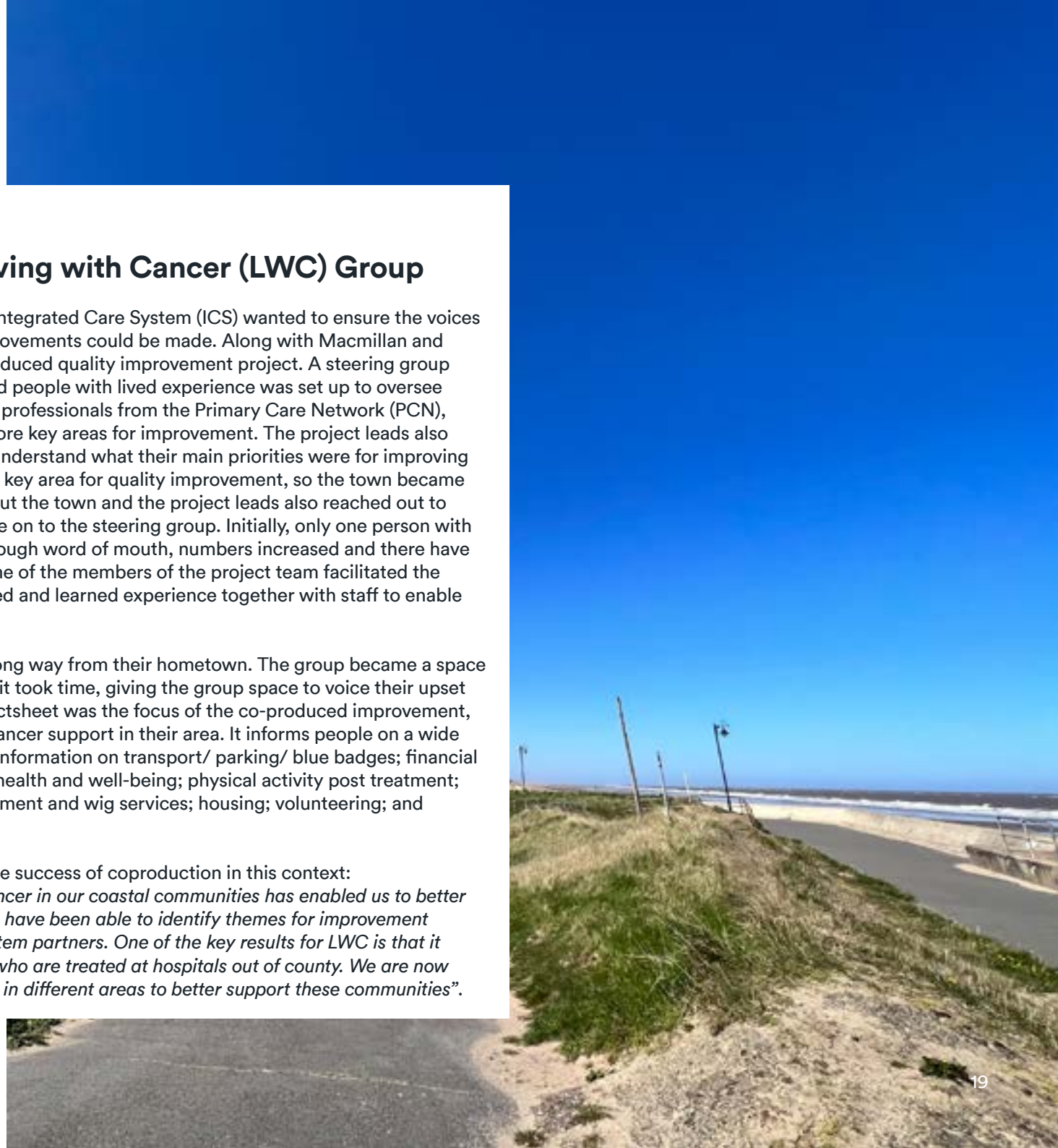
> "No doubt that people benefit hugely from taking part in research. It's very positive if done in the right way. It's a really positive experience. It makes a huge difference to the way people often feel about their conditions and you know, some studies again, if they're interventional, they're receiving much more on top of care as usual… we've just done a dissemination event on a study we ran about strength and balance in early dementia and again people got physio assessments, OT assessments, a series of visits from rehab support workers and to participate in that programme over many months. So regardless of the outcome of that research, the feedback that we've got from our participants and their carers that took part is that it was a hugely positive experience for them, full stop."
>
> **Manager NHS**

Case Study:
Every One and The Mablethorpe Living with Cancer (LWC) Group

Rates of cancer in the East Coast are high so Lincolnshire Integrated Care System (ICS) wanted to ensure the voices of people living in these communities were heard and improvements could be made. Along with Macmillan and the charity, Every One, Lincolnshire ICS started this co-produced quality improvement project. A steering group consisting of members of staff from a range of partners and people with lived experience was set up to oversee the co-production project. They spoke to many healthcare professionals from the Primary Care Network (PCN), neighbourhood teams and GP Practices in the area to explore key areas for improvement. The project leads also approached people in the street in the East Coast area to understand what their main priorities were for improving cancer care. Mablethorpe was specifically highlighted as a key area for quality improvement, so the town became the focus of the project. Posters were distributed throughout the town and the project leads also reached out to the local community to recruit people with lived experience on to the steering group. Initially, only one person with lived experience of cancer joined the first meeting, but through word of mouth, numbers increased and there have since been five people who have consistently attended. One of the members of the project team facilitated the group and created a neutral space to bring people with lived and learned experience together with staff to enable initial conversations.

The people of Mablethorpe felt isolated as services are a long way from their hometown. The group became a space where they were able to share these grievances. Although it took time, giving the group space to voice their upset enabled the project to progress. Development of a local factsheet was the focus of the co-produced improvement, which aims to help residents of Mablethorpe to navigate cancer support in their area. It informs people on a wide range of services and the help that is available. It includes information on transport/ parking/ blue badges; financial support; aftercare/emergency care; prescriptions; mental health and well-being; physical activity post treatment; charity/ hospice support; spirituality and faith; dental treatment and wig services; housing; volunteering; and support for carers.

An NHS Cancer Services Staff Member has reflected on the success of coproduction in this context:
“Working directly with Every One and people living with cancer in our coastal communities has enabled us to better understand the expressed needs for those communities. We have been able to identify themes for improvement and action and to communicate those with Lincolnshire system partners. One of the key results for LWC is that it has highlighted the problems faced by our cancer patients who are treated at hospitals out of county. We are now working on improving links and pathways between services in different areas to better support these communities”.

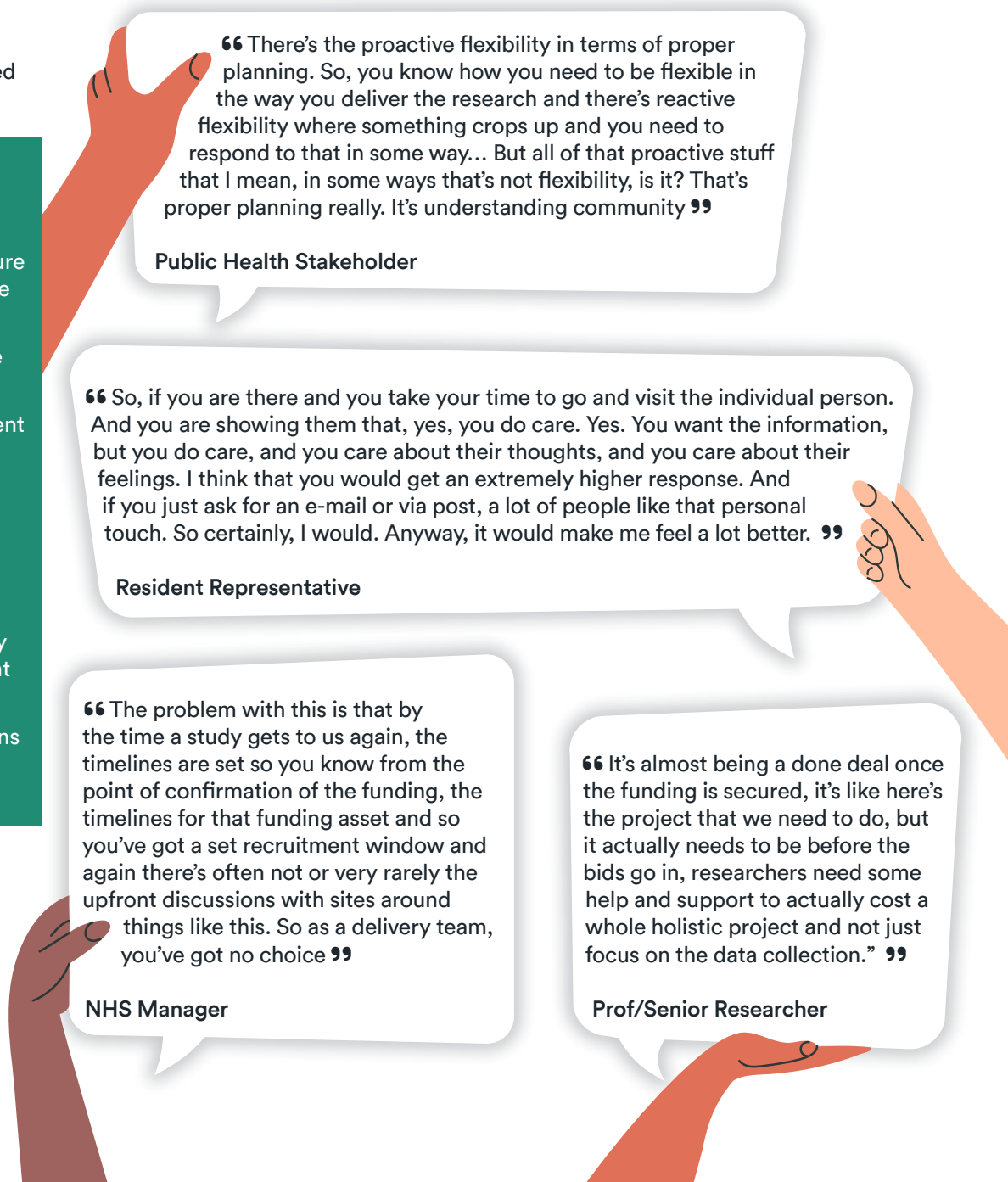


Core Guideline 6: Building flexibility into your research approach

Building flexibility into your research approach can be essential in enhancing participation of rural and coastal communities. This can take different forms, but essentially represents a departure from research that is informed by, and predicated on, assumptions of 'what works' for urban populations.

Guideline Dimensions

- As one participant described - being flexible can mean being proactively flexible whereby the research design plans for alternative approaches to secure participation. Reactive flexibility accounts for unplanned challenges not in the scope of the original proposal.
- Changes in methodological approach may be needed and at pace – are there identifiable ways research teams can add capacity.
- Researcher flexibility can mean accommodating seasonal peaks in employment and farming – consideration of where, when, and how data collection (and wider stakeholder engagement) takes place.
- Being flexible includes thinking about study governance, research ethics and informed consent and how marketing and communications may need to be different to urban approaches – attributing more time to 'in-person' contact.
- An informed approach to researching health and care in rural and coastal communities can mean different economies of scale. This includes potentially working with smaller sample sizes, using different approaches to engagement and data collection.
- Empowering stakeholders can include enabling dialogue and providing options for decision making about their involvement in research, at all stages of the study process.



Case Study:
Engaging Farming Communities in health screening and support: Lessons for research 'outreach'

Lincolnshire Rural Support Network (LRSN) is a volunteer-led organisation that provides pastoral and practical support to Lincolnshire's agricultural and horticultural communities during periods of anxiety, stress, and problems relating to their families and businesses. Serving the county for over 20 years, their mission is to harness the human and financial resources available to improve social and mental wellbeing of individuals in rural Lincolnshire through the provision of information and support. Recognising the under-engagement of these communities in mainstream health and care provision and challenges in accessing services for members of their communities, LRSN employs qualified healthcare staff who 'reach out' by taking support to their stakeholders. Nursing staff hold clinics in livestock markets in the county where farmers can drop-in and participate in health screening for diabetes, blood pressure and cholesterol and receive advice on healthy living and wellbeing, including mental health issues. The charity has recently added a 'health hut' to its services – a mobile consultation clinic that attends farm events and country shows. A core characteristic of their work is that it is peer-led and informed, recruiting staff and a family of volunteers who have background experience in rural life to promote accessibility to their services.

LRSN is engrained in the county and part of a wider network of Farm Support Groups nationally who are a trusted voice in representing farming issues. Their other activities include a helpline and one to one case work with individual farmers and their families covering a range of issues including knowledge sharing, business advice, and support with health and wellbeing. Immersive in its approach, LRSN develops lasting relationships and stakeholder trust enabling the collection of case studies, interview, Social Return on Investment and quantitative data from people who use their services. Head of Charity, Amy Thomas, describes the key factors that make LRSN a successful and valued rural community charity *"LRSN provides a holistic and person-centred collaborative way of engaging with our community members and this is integral to how we deliver services and promote the relevance of our research activity"*. An LRSN service user said that without this approach *"we would be in dire straits, and in one way or other we would not be here"*.

Core Guideline 7: The symbolic resonance of research in rural and coastal communities: Preparing for, and continuing with, 'emotional labour'

Research in rural and coastal areas has strong symbolic resonance, with complexions that include collective and individual identities, aligned to researchers, institutions, and communities. These factors can inform the development of studies and how to 'reach' and connect with multiple stakeholders. The dimensions of this guideline crosscut the previous 6 Core Guideline areas.

Guideline Dimensions

- Researchers can gain trust from communities by considering the challenges and needs of communities, developing partnerships with trusted and embedded organisations and stakeholders and being situated in communities.
- Planning community engagement and research to generate public interest with underserved communities can form effective strategies to overcome apathy.
- Showing commitment and spending time are enablers of participation. Their symbolic nature can indicate how studies can be scaled up and/or closed down.
- Manging the risks to communities includes developing project communications and promotion so research and dissemination are not misinterpreted or damaged by third party representatives. Particularly in settings that are politically sensitive and/or where levels of multiple deprivation are high.
- Managing expectations of multiple perspectives in coproduction, research planning and funders can be complex to navigate. In these settings the Maryland 'gold standard' of clinical trials/quasi experimental design might not be fitting or achievable

> "You have to really work to build a relationship. I think that's the thing… some developments we've got really good relationships with the Resident Representative on site, and we've got a good relationship with the Parish Council, and we get a lot of feedback from those developments"
>
> **Senior Housing Manager**

> "You need to use those local organizations who are working on the ground, know the population, but more importantly are trusted. They are trusted to do that work in the area."
>
> **Councillor**

> "Particularly from the research that I've done in Mablethorpe, Skegness areas, there's this deep undertone of lack of trust with services and with the professionals in those services. Some of that's driven by the amount of change they see and they're not seeing the same professionals consistently. So, they don't know them, they don't build up relationships. Also, they don't necessarily trust the motives. Why do you want to ask me that? What do you want to know that for? Those kinds of concerns come, and it takes time to build those relationships and that rapport"
>
> **Experienced Post-Doctoral Researcher**

> "We did commission some behavioural insights research onto some of the unique barriers (in Boston) and a lot of it came from, you know, they just, they just don't trust us. And so, there's a lot of work to do and it's difficult reading and it's very uncomfortable for a local authority to be told or the health system to be told… you know, we don't engage with you because we don't trust you. And we don't think you care about us. You know, it's a tough read, but I don't think that's been covered today. I know we're talking most around rurality, but certainly a barrier in Lincolnshire."
>
> **Local Authority Stakeholder**

Case Study:
The ‘Community Researcher’

Patient and Public Involvement and Engagement in research is established as a significant resource and mechanism for improving the quality of health and care services and their outcomes. The role of ‘experts by experience’ in coproducing dialogue and service development is recognised in NHS policy. In 2019 the NIHR release UK Standards for Public Involvement in research comprising of 6 Standards, which are: Inclusive Opportunities; Working Together; Support and Learning; Governance; Communications; and Impact. Each provides guiding questions for researchers, enabling them to reflect on whether they have reached each standard. Public involvement in this toolkit has been critically important. The focus groups, interviews and project workshop engaged stakeholders from a variety of occupational backgrounds, as well as residents with lived experience of their own communities.

A Community Researcher, called Ava Harding-Bell, was recruited into the research team in the early stages of the project. Currently the Chair of Swineshead Patient Participation Group (PPG) in Lincolnshire, Ava has extensive county-wide links that bring local knowledge to the Toolkit, engaging other PPG leads who connect patient experience to professional development and practice in Primary Care. The Community Researcher model is an example of best practice that can be implemented across range of research projects, be these of rural, coastal, or urban focus. In developing the toolkit Ava has been instrumental in engaging the whole research team, the Lincoln International Institute for Rural Health and wider University with close-knit communities who may be underserved or feel disengaged from Higher Education and research institutions. Ava’s role (and the potential contribution of other Community Researchers) is collaborative, grounding researchers by ensuring technical and institutional discourse is translated into information that is accessible and appealing to a range of residents – specifically those without academic and research interests. Ava reflects on the added value of Community Researchers: *“We’re on the ground all the time and with all the other (committee) work that we do, we are able to actually get through and have constructive conversations that do actually change things.”*

Toolkit Checklist

Developing strategies for involving rural and coastal communities in health and care research.

- [x] Have you considered limitations that 'objective' definitions of 'rural' and 'coastal' can have, especially when seeking community engagement and collaboration.
- [x] Have you attempted to identify formal gatekeepers (such as health professionals, local authorities, and community development representatives) and informal gatekeepers (such as residents).
- [x] Are their local complexities of 'place' which your research conduct needs to be mindful of (these may include demographic make-up, environment, multiple deprivation, local economies, health and care needs, and gaps in provision, alongside community services and assets).
- [x] Does your budget cover networking, and the recruitment and retention of Community Researchers costed into the project as part of the Team.
- [x] Have you considered the costs that may be involved in supporting participation where practicalities prevent inclusion.
- [x] Does your budget include participants being paid for their time (including travel) to replace expenses and loss of earnings.
- [x] Are their implications for refining your sampling approach and size – what is feasible in rural and coastal settings compared to urban areas.

Overcoming the shared challenges of the effective delivery of health and care services and engaging communities in research.

- [x] Do you take into account finding out what the rural and coastal inequities are for residents' engagement both with health and care services and research processes.
- [x] Can you identify best practice in approaches to implementation.
- [x] Is culture-change for policy makers, research governance and funders, as well as providers and residents a barrier and/or enabler for your study.Community assets and strengths can shape services and research opportunities – do you have an approach in place for identifying these.
- [x] Have you identified gaps in, and barriers to, quality service provision that are instrumental in building and demonstrating an understanding of lived experiences within communities.
- [x] Is the centralisation of both services and research activity a challenge for reaching people in rural and coastal areas.
- [x] Have you evidenced/or will you evidence the potential health and wellbeing resources and/or benefits of rural and coastal places.

Identifying and working with ‘underserved communities’ to understand their needs, behaviours, and preferences.

- Is a feasibility and/or exploratory study accompanied by community engagement built into your study? Will this be used to identify and understand complex and underserved communities.
- Can you think of residents or community stakeholders who might be intentionally and/or unintentionally ‘hidden’ from their ‘place’, services and research.
- Have you included seasonality as part of coproduction, design and timing of research approaches which may impact participation (e.g., peak tourism, hospitality, and farm businesses).
- Does your research recognise that communities, and specific sections of rural and coastal populations (including practitioners/professionals,) can be subject to multiple evaluation activities and research fatigue.

The value of positive and flexible approaches to communication in reaching stakeholders.

- Have you thought about infrastructure being a barrier to participation that you need to address – including factors such as transport, connectivity and people living ‘off-grid’.
- Does your research/evaluation demonstrate sensitivity by flexibly adopting approaches for different sections of rural and coastal populations.
- Have you considered how, when, and where to promote studies and positive empowerment of ‘gatekeepers’ (be these official representatives or informally well-known points of contact).
- Will your research include ageing rural/coastal communities? Will you need to think about changing function and communication needs of the local population.
- Have you planned to undertake ‘formal’ communication through research materials, partnership promotion as well as including ‘informal’ communication (in situ and taking advantage of existing trusted people, organisations and places).
- Will you engage lived experience over the project life-course from pre-design to post-project completion.
- Will cultural awareness training be required and/or have you consulted the Toolkit for increasing participation of BAME groups in health and social care research.

Promoting the relevance of health and care research.

- Have you communicated the potential links between research and the health and wellbeing of communities without over-promising.
- Will you have continued presence of research staff, teams and institutions in communities that are linked to policy, strategy, and practice.
- Are sensitive approaches to people in rural and coastal communities recognised.
- How will you challenge possible perceptions that researchers and Universities are physically and ideologically situated in urban ivory towers.
- Will your study be part of a longitudinal relationship whereby researchers have ongoing contact with communities.
- Do you plan to use forms of outreach as a deeply symbolic mechanism of including communities, organisations, and individuals.
- How will you secure and coproduce PPIE.
- Will information include technical and accessible 'easy read' versions.

Building flexibility into your research approach.

- Will you be proactively flexible whereby the research design plans for alternative approaches to secure participation.
- Will there be project team capacity to support reactive flexibility (where measures can be taken for unplanned challenges not in the scope of the original proposal.
- Does your research team have research skills capacity, so changes in methodological approach can be implemented (and at pace).
- Will you use greater 'in-person' networking and relationship building.
- Are you prepared to work with potentially smaller sample sizes, and use different approaches to engagement and data collection.
- How will you empower stakeholders? Will you provide different options for people to make decisions about their involvement in research, at all stages in the process.

The symbolic resonance of research in rural and coastal communities: Preparing for, and continuing with, 'emotional labour'.

- Is trust between researchers and communities an issue.
- Will/have you developed partnerships with trusted and embedded organisations/ stakeholders by being situated in their communities.
- Can community engagement events and activities heighten public interest from underserved communities.
- Is apathy to research and professionals an issue.
- How will you show commitment to communities? Have you planned for spending time at community venues to enable participation.
- How will you manage, communicate, promote, and disseminate your project to avoid misinterpretation or damage from third party representatives (particularly in settings that are politically sensitive and/or where levels of multiple deprivation are high).
- How will you manage expectations of multiple perspectives in coproduction, research planning and funders to ensure a positive legacy for future researchers.

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