



Community Led Engagement & Research Project Report

September 2024



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Summary Overview

The aim of the Community Led Engagement and Research Project was to maximise opportunities for people to participate in health and social care research. Bringing the topic of research to underserved communities, increasing local engagement and identifying health inequalities experienced by diverse groups. Herefordshire is largely under-researched, very rural with dispersed populations.

The combination of poor public transport and lack of reliable broadband services and mobile network coverage makes accessing health and social care appointments, studies, trials on and offline a challenge. Under these conditions engagement and participation in research is complex and disparate, leading to inconsistency of contribution across communities and a difficulty to create long-term local relationships with key contacts which can be nurtured, built upon and developed. It is important that researchers hear from all parts of the community, identify the most needed studies and establish the best ways and methods of participation and engagement.

Introduction

Healthwatch worked within Herefordshire communities to raise awareness of health and social care research and promote how people can get involved. Recording views, opinions and ideas on the best ways for communities and individuals to participate in research projects long-term and create change. The project primarily focused on engaging people living rurally, farming communities, domicile traveller communities, unpaid carers and anyone struggling to engage with regular healthcare checks and screening.

Researchers were particularly interested to know the following to help them apprise what was needed to achieve successful sustainable engagement from individuals and communities in Herefordshire:

- What do people understand health and social care research to be?
- Have they ever been involved in research before?
- What would motivate them to participate in research?
- What barriers would deter them from participating in research?
- What considerations would need to be made before participation took place?
E.g. belief systems, values, attitudes, cultural and ethnic origins.
- What types of research would they like to be prioritised in the future?
- What research is relevant to them and their community?
- Would incentives be needed for sustainable participation?

- Would they prefer working in groups or as individuals?
- Which models of engagement work?
- What will keep people engaged with researchers in the long term?
- What would people like to learn about research?

In summary the information collected will inform the basis of an engagement toolkit which researchers can use when working with communities. In addition we were able to identify which research topics were a priority to the public and what would motivate the public to get involved. Barriers to participation were also highlighted which can now be addressed to make research more inclusive in Herefordshire.

Methodology

Healthwatch identified organisations and groups working with the target cohorts and engaged with trusted individuals to ascertain the best ways to encourage participation. Community meeting places and hubs were also contacted to ask for their assistance in promoting the project and encouraging participation. Emails were sent out to a wide range of community contacts containing an overview of the CLeaR project including a link to a questionnaire to enable them to share easily with other professionals and those they are supporting. Posters and literature were left at community hubs to be displayed or distributed. Engagement Officers visited community spaces across Herefordshire to speak with the public and met with professionals in their workplaces or at online meetings.

In addition the following marketing and data capture mechanisms were put in place:

- A questionnaire was created to collect direct and open ended responses from individuals. This offered a mechanism to record opinions, views and comments in a standardised way for easier analysis and has been invaluable.
- Healthwatch Herefordshire created two short films about Health and Social Care Research which sets the context for initial discussions with the general public and explains the ways to get involved.
- A project logo was created so that it is recognisable alongside all of the other research activity taking place within the region.
- A set of posters were created to publicise the project and to encourage involvement, these included a QR code to the project questionnaire. Electronic versions of these were shared with partner agencies to be included in newsletters, printed off or shared on their social media channels.

- A series of social media posts dovetailed the posters and were shared and partners were tagged to encourage their cohorts to get involved.

Demographics

- 94 responses were received and recorded on the questionnaire. The highest number of respondents were categorised as living rurally.
- Responses were received from across the whole of Herefordshire with just over half originating from North Herefordshire, Ross-On-Wye and Hereford. The rest were split between market towns and various village locations.
- Most responses were from people within age group 25 - 79 years.
- Fewer responses were received from young people 17 - 24 years.
- Female respondents were twice that of males, with a very small percentage preferring not to disclose their gender.



80% of respondents had never taken part in any kind of research.

Key Findings & Community Feedback

What do people understand health and social care research to be?

Most participants had heard about clinical research due to the exposure given via media channels. However others had not ever been introduced to health and social care research and knew very little about it or how to get more involved. When asked to define health and social care research a variety of responses were given, the most common ones are collated below:

- Research in social care could be about introducing new devices and technologies such as: lifting equipment to help with residents, exploring the impact of technology driven care environments or changing social care policies and practice.
- Information gathering from people with lived experience to identify and implement best practice. The study of the wellbeing and welfare of people.
- Research to help inform policy direction and allocation of resources to treatment and social care environments. Also to help diagnose and treat people better.
- Looking for different ways to better deliver and understand health or social care need.
- Finding out about new treatments, what works for different conditions.
- The reviewing and analysis information collected, leading to the development of new approaches and operation of services.
- Knowledge that could lead to new treatments, policies and care.

- Research which makes health solutions or care provision better.
- Researching what matters to people regarding their health and trying to make improvements to medication or services.
- Making things better for people, finding ways to improve lives through medication or services.

"I have always thought that health research was about clinical trials."

Have they ever been involved in research before?

A small proportion of respondents have been involved in research before, the list below details the level of their participation.

- A lifelong survey of Women's' health at Oxford University
- Long term participant in the UK Biobank project
- Surveys with NHS, Healthwatch, GP surgery and hospital.
- Studies into women's' health.
- Assisting with a social prescribing project.
- Cancer studies and Alzheimer's research.
- NHSE Digital Urgent and Emergency Care Committee member.
- Drug trials.
- Study on fibromyalgia.
- Involved in a review of informed consent across all care.
- Trial and review of treatment and drugs for Nottingham University for arthritis.

What would motivate communities to participate in research?

Through direct conversations and online responses there were a number of motivators which came up repeatedly, the most popular reasons for people to get involved in research were:

- Improving health and social care for others.
- Having a difficult health or social care experience and wanting something positive to come from it.
- Wanting to learn more about a condition that they or a family member or friend has to be able to support them better.
- If it was easy to take part.
- If the topic was of interest to them.
- Wanting health and social care to be improved for future generations.
- If the research would be beneficial to others.

- Being able to make a difference to peoples' lives.
- Being able to give something back after receiving care themselves.
- If the research was relevant to them.

How would communities most like to be involved in research?

Although most of the public who were consulted had never taken part in any kind of research, when asked if they were to become involved how they would like to participate with researchers, the most popular responses were as follows:

- Making sure research focuses on the most important topics.
- Giving researchers new ideas for research.
- Making sure researchers ask the right questions.
- Making sure that any written materials are clear, easy to understand and include the most important information.
- Identifying how best to support people who take part in research.
- Sharing their experiences.

Respondents were open to receiving research information or opportunities in many different ways, newsletters, text, online meetings or in person at a focus group, the top choice however was via email, provided it was from a trusted source.

What training and support did communities identify they would need to participate in research?

There was a clear theme from responses that members of the public did not fully understand research or the role of researchers, and identified the following areas of training and support they would need for successful participation. This could be provided in person, in group settings or online as learning modules.

- Introduction to understanding health and social care research, the difference between the types of research and most importantly the role of researchers.
- A guide on how to get involved in research and what you would need to know and do as a citizen researcher.
- How to work with researchers, what are the expectations and level of knowledge required and understanding what researchers want from public participation.
- Learning about the benefits of research and hearing about successful research projects.
- Understanding the jargon used in research.
- Training on specific research projects and how best to collect research information for researchers.
- Training to be able to feel confident to communicate about research with others.
- How to approach the public about research, role play, understanding the barriers.
- How involvement in research will make a difference.

- A walk through of previous research projects, how public involvement shaped these and what the outcome was.
- Literacy support.
- An overview of how the health system works and where research comes into this.
- Interpreter support.
- IT training.

What were the areas of research that communities identified as being important to them?

Discussions with members of the community resulted in a wide range of research topics being suggested. These have been collated into categories for ease of reading.

Hospital, GP Services, Dentists, Health Care, Social Care

- How lack of transport provision in a rural county impacts attendance at GP or hospital appointments, affects waiting lists and ultimately patient outcomes.
- Patient discharge process from hospital, what could be done to ensure better patient care in the community and recovery?
- Improving accessibility to health care sites (GPs, dental surgeries) for those with disabilities using mobility scooters, wheel chairs etc.
- Financial impact on disabled residents where no suitable public transport exists to take them to appointments and they have to access private alternatives.
- Review of the current GP system, is it helping or hindering patient's recovery and health.
- How to improve training in residential care homes to improve care and outcomes.
- How Artificial Intelligence can improve patient care, what benefits can it bring and in which areas.
- Incontinence, a study on the impact on the environment (use of adult nappies), measurement of waste. Look for alternative ways to manage the issue.
- Pain management pathways and medication, how to ensure patients avoid opiate addiction.
- How to improve outcomes for those living with long term health conditions.
- If connecting health service records and improving communication between health professionals would reduce costs in the NHS and improve patient care and outcomes.
- Dental health and investigating the link between this and overall heart health and general wellbeing. What impact is the lack of available regular dental care having on people's wellness and what other issues are caused by bad dental hygiene, how this can be improved? Would be interesting to see the effect over age ranges. It would be helpful to establish what could be done to improve

dental healthcare access and how this in turn would improve health overall and how much money this would save the NHS.

- Revision of the overall health service, the existing structure doesn't work, with social care being organised by local Government, GP practices operating independently via contracts and hospitals working within new area structures. The current approach is causing a miss-match of provision.
- The funding and operation of social care in the community.
- How to provide better health provision and healthy activities in rural areas to improve community health.
- Does private healthcare reduce waiting lists for those who can only access free NHS care or does this increase health inequalities? How private health care is influencing access for those without funds.
- End of life care pathways, what options do patients have?
- Is the NHS trying to offer too many non-urgent services free e.g. cosmetic surgery, should it be concentrating on providing less core services and if it did what would the impact on waiting lists and budgets.
- Would an increase in early screening of patients for more conditions conducted with a preventative mind-set lead to better survival rates and outcomes for patients.
- How best to engage men in their 50's and 60's with health checks and initiatives.
- How the lack of access to proper dental care is affecting cancer patients in terms of delaying their readiness for chemotherapy treatment.
- Is reduced patient access to GPs making more patients rely on 'Dr Google' for health remedies and diagnosis? How is this affecting health outcomes or is it burdening GP practices more?
- What is the best way to ensure parity between GP surgeries for health checks e.g. prostate and reduce the perceived lottery effect for patients?
- Research on the use of catheters and how unnecessary prolonged use affects the outcomes for patients and whether an improved process leading to early removal would significantly reduce infections and improve patient outcomes.
- A study on assisted dying would be interesting to see what the public's perception of this is, how it would work with appropriate safeguards, what is happening in other countries and what impact that would have on patients and their families if they were given a choice about how they want to die. It could also open up conversations about dying which we in the UK are not good at. What would be the impact on palliative care, medical staff, dying pathways and government policy?
- What is the impact of delayed discharge from hospital for those living more rurally who have less access to support at home due to travel distances for health professionals and poor local amenities?

- Ambulance response times. Are rural outreaches having worse response times than before? Can anything be done to make response times more equitable, especially with very serious conditions/accidents?
- A study which looks at the impact of forced isolation for elderly people in rural locations and what could be done to improve the life span and quality of life for older people within rural communities.
- Health inequalities and their impact on long term health.
- Research on the effects of statins. Are some statins causing more problems than preventing them when prescribed by the GP? A study into the use, benefits and side effects of statins would be really beneficial. It would mean that patients could be better informed as to whether they actually need them, what effects they may have and also whether they could make some key lifestyle changes that may provide them with a similar outcome but without having to take medication.
- The impact on patients when health services (GPs and Hospitals) do not communicate with each other or have the ability to see patient notes and the bigger picture. How does this affect diagnosis? What delays does it cause in treatment? How does this affect recovery and overall outcomes? How much does this inefficiency cost the NHS?
- A study on how veterans can be supported better when they leave service both in regards to health checks and available services and the impact this would then have on reducing mental health conditions, suicide and homelessness.

Young People

- Learning and development opportunities for 19–25 year old individuals with complex needs – opportunities are lacking, how this would improve outcomes.
- Research the effects of domestic abuse on young people and their future relationships. What services could be put in place to help them manage their mental health and build resilience for the future.
- Research what impact children's social prescribers would have on the health and wellbeing of young people and whether this would reduce waiting times for assessments, mental health need, reduce truancy and generally improve outcomes etc.
- Research why there is a prevalence of men and boys in the Gypsy, Roma and Traveller community with learning disabilities, ADHD, autism or aspergers. Why this is occurring and what care and support could be offered in early years to help them manage the condition, and if this is linked to the high rate of suicides.
- Study the cohort of children who are falling between the gaps in accessing mental health services when moving between one health authority to another due to bureaucratic processes, this also includes information sharing with schools and colleges. Has this led to an escalation in mental health issues for

young people where early interventions have been delayed? What could be changed to improve outcomes for young people?

- Special needs and medication. ADHD - age limits to have certain medication which vary between different health authorities. What difference does this make to families and children? Paediatrics cannot prescribe medication so it has to be CAMHS where there are huge waiting times for young people to be seen. What impact is this having on recovery or is this worsening the condition?
- SEND provision is variable and almost non-existent in some areas, what impact is this having on children and how can this situation be improved? How can parents be better informed about how to navigate the SEND support system?
- Education Health and Care Plans (EHCP) reviews. What consequences are there for authorities not meeting deadlines? What impact is this having on families and children with no timely EHCP review plans or action?
- Research into Adverse Childhood Events and study the impact these have on young people, their future health, aspirations and outcomes.
- A study on the effects of bereavement experienced during childhood and how this can limit achievements, outcomes and drive young people into risky behaviours and drug taking would be beneficial and may shape new services and improve existing ones. Schools, colleges and workplaces could benefit from the findings and learn about how to deal with it better and provide a bigger choice of support for young people.

Mental Health

- How lack of timely mental health support is affecting the population's wellbeing, particularly young people.
- How to reduce suicide rates amongst people with ASD and neurodiversity.
- Research into why male suicide is higher in Gypsy, Roma and Traveller communities and how this can be tackled and reduced.

Men

- How lack of appropriate housing for single males is affecting their health.
- Researching the best ways to give the farming community opportunities for health checks and see if this improves farmer's health and wellbeing. Would more flexibility in GP access offer better outcomes? Some farmers are predisposed to certain conditions which family members have and yet are not raising this or seeking help.
- Research how to improve diagnosis and treatment for men experiencing prostate issues. Advice can vary greatly in terms of whether they should have their prostate removed or indeed when, including what side effects this may cause. There seems to be concern about risks of becoming incontinent after operations and then experiencing a reduced quality of life. It would be beneficial

to have a prescribed pathway to enable men to make better choices depending on their circumstances and age. There has been conflicting information on PSA levels and whether that means an immediate diagnosis of cancer or can be attributed to other issues. More comprehensive studies around this would be beneficial.

Women

- Research the best ways of offering menopause advice and support via health practitioners that is consistent and up to date, has some depth of knowledge and makes a difference to women's lives. Covering topics such as HRT options, risks, how to identify if experiencing perimenopause or actually going through the menopause and managing symptoms. Also due to the inconsistency of approach and information, research what this is costing the NHS to treat, impact on businesses in relation to absence and how many women are removing themselves from the workforce due to the adverse effects of menopause. Also if a proper pathway was put in place the improvement in outcomes for women.
- Study on the health inequalities for Gypsy, Roma and Traveller women accessing maternity care, identify areas of deficiency, inconsistent care and what is needed to improve outcomes for women and their children within this community.

Carers

- Impact and health deterioration of long-term carers, what provision could be put in place to assist carers and reduce this?

Isolation & Loneliness

- Best ways to support an ageing population living in isolated rural locations.
- Ways to reduce rural isolation, poverty and homelessness to improve health.
- The health implications of rural living for elderly people particularly where there are almost no amenities, regular bus services or activities in villages. How can the health of this forgotten group be improved?
- The effects of rural isolation, where there are no available services or amenities to access except for the GP surgery. Where people just don't see anyone from week to week or have a chance to come together, particularly in the winter. How does this affect mental health and their motivation to take care of themselves properly?
- How the demise of cohesive communities is affecting the health, wellbeing and aspirations of families living on the edge of poverty.

Cancer

- How a holistic approach to health issues could improve outcomes for cancer patients. Widening the focus from just the cancer treatment, looking at the bigger picture including other ailments the individual is managing alongside and identifying the support those caring for the individual need to aid recovery and avoid any detrimental effects to their own health.
- Research into all types of cancer, proactive screening, best treatments and medications. What would improve patient care and outcomes?
- Study why the UK appears to be the worse place for early diagnosis of cancers and treatment in Europe despite ever more money being pumped into research? What needs to be changed?

Dementia

- Dementia - solutions for care and better treatment. Do people with more family involvement fair better than those who are rurally isolated and alone and who only ever see a health professional?
- Better understanding the causes, symptoms and management of those with alcoholic dementia.
- How communicating better with dementia patient carers could avoid unnecessary distress and pain.
- Dementia is a very important issue, especially for those isolated and living in farming communities or rural villages that may not have family nearby. If undiagnosed or diagnosed with dementia but with limited care provision many people are left to manage the condition and have very poor outcomes. Remembering to attend clinical appointments, take medication or even just eating can be an issue and many services although great for information and advice, do not provide a wraparound service. So the quality of life is generally poor for these people, missed appointments, lack of interactions with health professionals. A study on a better way to manage dementia within communities would be very helpful. How do people manage? What works best? What could be improved? How can we improve people's quality of life while managing this disease?
- A study into dementia in the homeless population, how is it managed given that the person is moving around and may not access consistent healthcare. How do the outcomes vary from those in permanent accommodation and care?

Diabetes

- Study how to make the public more aware of the early symptoms of diabetes, what lifestyle changes can be implemented and how this condition can be managed before it becomes a long term health condition.

Cultural Needs

- Research into the training required for health professionals to understand cultural needs. E.g. women need to be examined by women and not men. Many women in minority groups are choosing not to go to hospital appointments as they have had a bad experience. Professionals need to understand what experiences minority women have had e.g. maternity care, medical investigations and make adjustments where needed.
- Study into the needs of refugees coming from war zones, the effects of resettlement and the effects of restrictions to working and providing for their family. Impacts relating to anxiety, depression, future prospects, health and wellbeing.

Genetic Diseases

- Research and understand caused of autoimmune diseases, how they occur, has there been a recent upsurge in them and are they genetic? What the public need to do to improve their outcomes and manage conditions.

Neurodivergent Individuals

- Research into how many ND people are homeless? Does their condition predispose them to this? Is there a link? How can outcomes be improved for them and risk of homelessness prevented.
- There has been a significant increase in children and young people experiencing complex learning difficulties and disabilities, is this due to environmental factors, lifestyle choices or something else?
- Have improvements in maternity care and therefore a consequential increase in survival rates for children with complex needs created a larger financial burden for the NHS and lower quality of life for them?

What barriers to participation in research did communities identify?

The most common reason given as a barrier to participation was that individuals did not feel that they know enough about research and could make a meaningful contribution. Many had the perception that all research was clinical. Other perceived barriers are listed below:

- Many individuals reported that their lack of confidence would prevent them from getting involved, that they would feel intellectually inadequate when working with a researcher.
- Perception that if they did get involved nothing would change.
- A distrust of all things medical and government related, not wanting to share their data with authorities.
- Time constraints, many working people and carers did not think they would have enough available quality time to participate fully.
- If participation did not lead to change or making a difference or if they were not told of the outcome of their contribution.
- Having to travel long distances to participate and incurring expenses.
- If there wasn't a reward or incentive for participation.
- Not wanting to disclose health issues.
- Apathy about research, not being able to see how research improves lives.
- If participation is too long winded, not fun or not relevant to the individual.
- If digitally excluded, less likely to feel able to participate.
- A chaotic lifestyle, being homeless or a victim of domestic abuse may result in not be able to participate fully and regularly.
- A disability (learning or physical) which may preclude individuals from participating.
- Language, literacy and cultural issues.

Shaping up a Community Research Toolkit

What did communities think were the best ways to engage them in research?

In most cases people reported a lack of knowledge around research, its benefits and successes, so felt that in the first instance there should be an awareness raising campaign to educate communities around the topic. This should incorporate a range of ways that people or groups could flexibly participate, online or offline.

Other suggestions included:

- Visits to community groups, sports clubs, voluntary organisations and businesses.
- Recruit local advocates trusted by their neighbours who can promote research within their communities.
- Encouraging health professionals, GPs and other practitioners working in communities to share the word about how to get involved.
- Posting flyers to households in communities.
- Using local social media village, interest and support groups to raise awareness and request involvement.
- Articles in local community newsletters.
- Hold local events to raise awareness and recruit participants.

- Use different media to attract interest from different age groups.
- School projects to raise awareness with families.
- Pub quizzes to educate people about research in a fun way.
- Go to local hubs, community centres and pubs to talk about research, just keep discussions non-political.
- Publicise and promote research more, the successes, illustrate how it has benefited people or the local area.
- Create a good space and opportunity to talk either online or in local familiar venues with refreshments.
- Create studies that have local relevance and will resonate with communities, they may be more likely to get involved.
- Visits to rural shows and charity farming events which attract specific target cohorts.
- Contact with farming support organisations like the NFU, Herefordshire Rural Hub, Young Farmers and 'We are Farming Minds' to publicise research and encourage participation.
- Involvement in 'We are Farming Minds' monthly events for farming families e.g. 'One Foot in the Grain', comedy nights and farmer's breakfasts.

Where were the best places to run research sessions within the community?

- It was clear that rural and farming communities wanted research sessions run in their local community centres, hubs, cafes, clubs, village halls, churches, schools, colleges or within established support groups. GP surgeries were also a popular suggestion.
- In regards to the Gypsy, Roma and Traveller community these would need to occur on traveller sites as most women within the community do not drive.
- With refugees, within their current, trusted meeting places with support staff and available interpreters if needed.

Which types of incentives would encourage participation in research?

Monetary incentives were low on the list of motivators identified to get people involved in research. However reimbursement of expenses, mileage and vouchers were of interest. Sponsorship of community events and coffee mornings were also mentioned. Training and personal development was also seen as a useful incentive, topics of training suggested were:

Menopause | Men's Health | Dementia Awareness | Heart Health | Basic First Aid | Digital Exclusion | Stroke & Head Injury | Understanding Primary Care & Matching Expectations | Meet the Researcher | Health & Social Care Research | Managing Mental Health | Supporting C&YP | Mother & Baby topics | The Role of Social Prescribers | Defibrillator Training | Meditation | Report Writing |

Additional Findings

Farming Community

- Encouraging participation from members of the farming community was quite challenging due to their working hours.
- Some of the most informative conversations took place at Hereford livestock market in the café where the farming community converge each week.
- Many farmers reported a lack of time to get involved in research, however did discuss health concerns and delays in engaging with testing and screening.
- The known topics around isolation, mental health and heart issues were acknowledged with varied levels of interest in being part of the solution.
- Assistance from charities and organisations already supporting the farming community is key to publicising research opportunities and encouraging participation.
- Participation may have to be done on a one to one basis at home locations to fit around the commitments of the farming community unless opportunities arise at farming celebrations, shows and events.

Gypsy, Roma and Traveller Community

Gypsy Roma and Travellers are among the most disadvantaged people in the country and account for approximately 3% of the Herefordshire population. Health outcomes for this community are very poor compared to other ethnic groups and they are more likely to be GP unregistered. Healthwatch has focused on engaging and building trust with the local GRT community with the aim of reducing health inequalities. This engagement has been achieved through productive partnership working with Herefordshire Council, Travellers Times and local community leaders and contacts, resulting in direct engagement on sites. A recent event hosted by Healthwatch celebrating Gypsy, Roma and Traveller history month allowed Healthwatch to engage with representatives from the community, to understand the barriers to accessing care and to recognise priority health issues. This initial research and groundwork has resulted in a successful bid for a GRT community connector who will now build on the existing Healthwatch engagement work to deepen ties and improve health care provision for this population.

It was important that we focused on the Gypsy, Roma and Traveller community to ascertain a better understanding of their health inequalities and which areas of research would be advantageous to them. We concentrated on engaging members of the community from the eight sites run by Herefordshire Council. In order to do this we distributed literature at the sites, spoke with individuals, created closer working

partnerships with other professionals working with the community and held an exclusive event 'Helping Your Family Stay Healthy' for GRT families to celebrate GRT history month.

From this engagement and event we learnt the following:

- Many GRT family members are not registered with a GP or dentist due to either literacy and/or trust issues.
- Routine screening and checks are being missed as healthcare systems are not geared up to make adjustments to include this cohort, in addition to people from this community not declaring their additional needs. Appointment letters are sent out to individuals who cannot read them, where texts or a voice message would be more beneficial.
- GRT families have a high prevalence of young children with learning difficulties, particularly young males.
- Suicide rates are high amongst young males, causes are varied and aftercare levels are very inconsistent for those who survive.
- Many families do not have access to the correct medication or have regular reviews due to two issues, the first that professionals will not go onto sites and the second that the individuals are unlikely to attend GP appointments regularly.
- Maternity care and support is very inconsistent with lack of regular interaction with midwives and health visitors during and after pregnancy.
- Women reported not being listened to during childbirth by professionals and treated in a dismissive way.
- Education for young women is not encouraged beyond primary school which impacts on their development and health outcomes.
- Many health professionals do not understand the culture of the GRT community, their ways and customs. A one size fits all approach is usually used and this then results in alienation.
- Reports that conditions are not identified early enough, or managed well when they are, resulting in worse health outcomes.
- Barriers to participating in healthcare – most women from this community do not drive and rely on others to take them to appointments. Men do not trust health professionals or there may be literacy issues which deter them from attending the GP surgery to avoid humiliation.
- Cardio vascular disease, respiratory conditions and diabetes are common ailments. Screening opportunities need to be taken to the sites to engage the community.

- Materials promoting healthcare services should be produced simply and perhaps with more illustrations so more easily understandable.

Homeless Community in Herefordshire

- Many individuals within the homeless community reported that they did not have the time or head space to get involved in research. Just managing day to day was enough to cope with. There was definitely a mistrust of authority and society and also a feeling of why get involved, it won't help me. The homeless individuals that we spoke with also said that they never really knew where they might be due to their chaotic lifestyle, as other things took priority so this too could be a problem with building a regular group of contributors.
- Cash incentives or vouchers were more important to this cohort.
- Digital exclusion was also cited as a barrier to involvement for this group although not in every case.
- Commitment level and the recognition of the benefits of research were far lower.

Veteran Community

- Veteran individuals and groups take longer to engage, there is a lot of mistrust and contact needs to be consistent and steady. The formation of a research group from this cohort would need to be carefully planned, individuals nurtured to build trust and a clear way established to convey how research could benefit this group and how they could contribute. Reassurance that it would not be a waste of their time.
- The perception of some was that the NHS did not necessarily understand the needs of veterans and there did not seem to be any desire for practitioners to change this, so why get involved?
- It would be advantageous to get a wider spread of age ranges participating in research to ensure study topics are relevant and up to date.

Those struggling to engage with regular healthcare checks and screening

- There are many reasons that some people in rural areas don't engage with healthcare, from lack of transport options, being house bound, digitally excluded, from being omitted from the health process or simply isolated without friends and family to support them.
- Where there are strong communities these individuals are usually identifiable and seen as vulnerable, by building up stronger links with local community champions, there would be a bigger chance of engaging with these individuals through trusted local contacts.

- Without assistance from community contacts, GP surgeries and local healthcare professionals, this cohort could remain invisible and never involved in research or any other health consultations.

Carers

- Carers reported that they need more time and dedicated opportunities to get involved in research. They are time poor and unless there is some sort of provision put in place to release them from their caring duties for a short time it is very difficult to participate regularly and fully.

Afghan Refugee and Ukrainian Communities

- Working closely with trusted advocates is key to engaging this cohort.
- We have encountered issues relating to the services that the NHS provide and how these are accessed, expectation versus reality. In order to fully engage these groups around research, initial ground work would need to be carried out to inform participants of how the health system works. Some work has already been completed by Healthwatch where health leaflets, a tips sheet and film have been co-produced with the Ukrainian community to help them understand the NHS and the best ways to interact with primary care services. This has also been requested by representatives supporting the Afghan families in Herefordshire and will be included in Healthwatch activities.
- It is extremely important to observe cultural settings, build trust and ensure appropriate translation services are available during research sessions.
- Preparation is key to ensure that health topics are explained clearly and appropriately, with less jargon and more visual representation.
- Researchers should be prepared to invest a considerable amount more time in developing working relationships with these communities and be aware that it may be some time before discussions about general health move into research.
- It might be more time and cost effective to fund a trusted advocate to facilitate discussions on research with a researcher present.

Key Learning Points

- Trusted advocates are the key to engaging individuals and groups and building relationships within communities.
- It would be beneficial to have an active individual within each community group who has either been trained and research ready or has an interest in research to inspire others to get involved, acting as the interface between the community and researchers.

- Most people do not understand what health and social care research is when asked, in most cases they think it's about clinical trials. A more flexible approach to opening up the discussion should be taken, about general health first and then leading onto the research element.
- Engaging people in health and social care research has to be less academic focused. Language, materials and conversations need to be more people centred and resonate with their lives and experiences. Events like health quiz nights can open the door to discussions about research and educate those taking part.
- Feeding back to those who have taken the time to participate in the project is absolutely crucial, particularly with those in the seldom heard category. It is important that individuals are valued and that they hear back from us as to how their participation made a difference. It encourages people to stay involved and want to contribute again in the future.
- People have a preference for 1:2:1 sessions rather than groups, mostly due to lack of confidence and knowledge regarding the subject of research.
- Most people report that their motivation for getting involved in health and social care research is to make life better for others.
- Any research engagement needs to be more than one session, investment into building relationships with individuals and groups needs to be factored in to ensure sustainability otherwise researchers have to start from fresh each time they want to consult the public around a topic. This can take a considerable amount of time and effort.
- There are multiple barriers for hard to reach groups, the most obvious ones are language and trust. Literature must be designed to include and explain research more simply.
- Interpreters must be chosen carefully and confidentiality considered.
- Carers are time limited and only have small windows of opportunity to participate and this may not be on a consistent basis given their situation.
- Health partners and other charities have been very helpful in informing their clients about this research project. Working with the general practice Taurus Talk Wellbeing Hub has been very fruitful, collaborations have been formed to enable easier reach into communities.
- Individuals from the veteran community can take longer to engage, many have been out of the loop and there is a lot of mistrust. Contact needs to be consistent and steady.
- The GRT community are difficult to engage even through trusted sources and it requires considerable time to establish relationships and trust before they will

participate. The community reports being fatigued from requests for their views from various organisations where they do not then hear back about whether their contribution made a difference, or promises are not kept. Individual community members have reported being stigmatised by their own community for offering their support to agencies, which has subsequently resulted in them withdrawing their participation. In Herefordshire the few professionals who have been consistently working with this cohort and are trusted have been very helpful although cautious in order to protect their own relationships.

- Most people are very busy, happy to give a viewpoint or complete a questionnaire but do not have the time to be involved more long term.
- Incentives do not necessarily have to have a monetary value, these can also take the form of sponsorship of community events, coffee mornings, workshops or training.

Recommendations

- Identify, build and maintain relationships with key trusted contacts within voluntary organisations, faith groups and prominent persons active within communities who can encourage and facilitate individuals and groups to participate in research.
- It would be beneficial to recruit a network of volunteers (Citizen Researchers) who can be trained and linked to researchers. This would enable a solid and consistent communications link with communities to convey research requests and hold consultations. This is now underway in Herefordshire via Healthwatch's Wellness Watchers volunteer platform.
- Voluntary sector, faith organisations and informal support groups who have well-formed and trusted relationships with seldom heard communities and groups may benefit from receiving funding to conduct pieces of research with their clients. It would be useful to have a designated research champion within VCSE organisations who can be research ready trained and linked directly to researchers.
- More work is required on engagement of the GRT community building upon the work conducted via this project. Healthwatch has recently appointed a GRT Engagement Officer focused on health inequalities which has been funded by the Core 20 connectors 12 month funding from NHS England. This work has just commenced.
- More awareness raising campaigns need to be launched around health and social care research to educate the public of the benefits and why it is important to take part and how to do that.
- It would be advantageous to work with primary and secondary schools around education of health and social care research to embed understanding and

encourage participation from an early age. It was notable from our work with young carers that they would like to be more involved but their understanding of research and its impact was patchy.

- Opportunities for Q&A online sessions with researchers would be useful to pique interest and involvement.
- As research is quite a new topic for most people, it would be beneficial if researchers could put together a foundation module or session which the public could access or could be delivered by a key volunteer in the community. Many people we spoke with did not feel confident or feel they have enough knowledge and were hesitant to participate.
- There should be a wide range of incentives available for research participants to include vouchers, reimbursement of mileage, training opportunities, days out, events, shadowing researchers etc.
- Regular roadshows to raise awareness of research would be useful, showcasing successful research studies and projects and how the public can participate.

Acknowledgements

Thank you to the following groups and organisations for their help with this project:

- Talk Wellbeing Hub Hereford (Taurus Healthcare)
- Herefordshire Homeless Forum
- Hereford Veteran Support Centre
- Refugee Resettlement & Migration Support Group
- Ledbury Refugee Support
- Herefordshire City of Sanctuary
- Dream Your Future Families, Ledbury
- Talk Community Hubs
- Herefordshire Carers
- Herefordshire Council Gypsy, Roma & Traveller Education Support Team
- Travellers Times

Useful Information

1. [NIHR Reaching Out – a practical guide to being inclusive in public involvement in health research](#)
2. [Public involvement in Research](#)
3. [Research Champions](#)
4. [Being inclusive in public involvement in health and care research](#)
5. [Valuing the role of the voluntary, community, faith and social enterprise sector in social care research](#)

Appendix 1 – CLear Questionnaire

1. Which community group/s do you represent in Herefordshire?

- I live rurally
- I am from a farming community
- I am a veteran
- I am a migrant worker
- English is not my first language
- I am from a Gypsy, Roma or Traveller community
- I am someone who struggles to engage with regular health checks and screening
- None of the above
- Other (please specify)

2. Which area of Herefordshire do you live in?

- Bromyard
- Golden Valley
- Hereford central
- Hereford town borders
- Kington
- Ledbury
- Leominster
- Ross on Wye
- Village - North Herefordshire
- Village - South Herefordshire
- Village - East Herefordshire
- Village - West Herefordshire
- Other (please specify)

3. What do you understand health or social care research to be?

Open ended question

4. On a scale of 1 - 10 how would you rate your understanding of health and social care research? 1=no understanding and 10 = expert understanding

Scale rating

5. Have you ever taken part in health or social care research? If yes, please tell us more in the comments box, how were you involved and what was your experience?

- Yes
- No
- Don't know

6. Have you ever taken part in clinical research? (e.g. trialling a treatment or drug).If you answer yes, please tell us more in the comment box , how were you involved and what was your experience?

- Yes
- No
- Don't know

7. If you answered no to questions 5 and 6 above, what would motivate you to take part in health and social care research? (Please tick any or all that apply).

- I have had a difficult health experience and I would like something positive to come from it
- I have had a difficult social care experience and I would like something positive to come from it
- I would like to learn more about a condition that I or a family member/friend has
- I would like to improve health and social care for others
- I would like to contribute and give something back
- I would like to be useful in improving other people's lives
- I would like to be useful in discovering new treatments
- I have an interest in health and social care and would like to know more
- I would like healthcare to be improved for future generations
- I would like social care to be improved for future generations
- Ensuring the views of underrepresented groups are heard
- Being able to make a difference
- I will be able to use my skills and experience
- If the research was relevant to me
- If it was important to my friends and family
- If it was easy to take part
- If the topic interested me
- If it could fit around my lifestyle/ day to day activities

- Whether the research would benefit others
- Monetary incentives, vouchers or additional benefits e.g. training/ skills raising opportunities
- Be able to meet new people and widen my circle of friends
- Whether support is provided to participate
- Other (please specify)

8. If you did choose to participate in health and social care research, how would you prefer to be involved? Please select options from the list below:

- Giving researchers new ideas for research
- Making sure researchers work on the most important questions
- Making sure research focuses on the most important topics
- Making sure that any written materials are clear, easy to understand and include the most important information
- Helping researchers to avoid causing any distress through their research
- Identifying how best to support people who take part in research
- Helping funders to decide which projects are worth funding
- Helping to write a funding application
- Helping to design projects that make it easy to take part
- Identifying potential problems in project plans and coming up with the solutions
- Playing an active role in designing and delivering community specific projects
- Helping to collect the data and working with researchers to make sense of the results
- Helping to share the results with people who want to use them
- Helping to put new evidence into practice
- Other (please specify)

9. If you did choose to participate in health and social care research, how would you like research information or opportunities to be communicated to you? Please select all that apply.

- Via email
- Via a newsletter
- Via text
- Via telephone
- Via letter
- In person at a meeting
- At an online meeting

- Other (please specify)

10. If you did choose to participate in health and social care research, what training or support would you expect/require?

Open ended question

11. In your opinion which health or social care topics do you think researchers should focus on? What is most important to you or your community? If you can tell us why it would be helpful.

Open ended question

12. In your opinion what factors/ barriers would prevent people from taking part in health and social care research? How could these be addressed or removed?

Open ended question

13. Do you have any particular beliefs or values which influence your attitude to health and social care research?

Open ended question

14. In your opinion, what would be the best ways to engage people in your community with health and social care research?

Open ended question

15. If Healthwatch Herefordshire were to run some group discussion sessions on health and social care research in your community, where would be the best places to host these sessions?

Open ended question

Standard Healthwatch demographic questions were asked at the end of the questionnaire.

Appendix 2 – Marketing & Social Media Materials

healthwatch
Herefordshire

Every day in the UK, someone is diagnosed with a disease or a condition. The treatment and support they will receive will, at some point, have been informed by **health & social care research**

Get involved & help us to improve the health of people living in rural communities in Herefordshire

Have your say about which research gets done, how it's carried out & how it will benefit you and your community

Share your views, opinions, experiences & ideas

Let's work together towards a healthier future

Want to find out more?
Call or text Kerry on 07726 937276
kerry@healthwatchherefordshire.co.uk
www.healthwatchherefordshire.co.uk
Get in touch or scan the QR code to complete our questionnaire online

Talk to us...

healthwatch
Herefordshire

Every day in the UK, someone is diagnosed with a disease or a condition. The treatment and support they will receive will, at some point, have been informed by **health & social care research**

Get involved & help us to improve the health of veterans living in Herefordshire

Have your say about which research gets done, how it's carried out & how it will benefit you and your community

Share your views, opinions, experiences & ideas

Let's work together towards a healthier future

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Every day in the UK, someone is diagnosed with a disease or a condition. The treatment and support they will receive will, at some point, have been informed by **health & social care research**

Get involved & help us to improve the health of farming communities in Herefordshire

Have your say about which research gets done, how it's carried out & how it will benefit you and your community

Share your views, opinions, experiences & ideas

Let's work together towards a healthier future

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Talk to us...

healthwatch
Herefordshire

Gypsy, Roma and Traveller History Month Event
'Helping Your Family to Stay Healthy'
Exclusive GRT 'Drop In' Event

- Free coffee, tea, soft drinks and cake
- Children's tabletop activities
- Free goodie bag

Come & meet the Healthwatch team
Wednesday 5th June 2024
(Drop in anytime between 9.30am & 1.30pm)
The Kindle Centre (nr ASDA), Belmont Road Hereford HR2 7JE




Have your say

healthwatch
Herefordshire

Rural Communities
in Herefordshire

We need to hear from you

Every day in the UK, someone is diagnosed with a disease or a condition. The treatment and support they will receive will, at some point, have been informed by **health & social care research**

Have your say about which studies & research gets done, how it's carried out & how it will benefit you and your community

Share your views, opinions, experiences & ideas
Help us to improve the health of rural communities in Herefordshire



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Talk to us...

Get in touch or scan the QR code to complete our questionnaire online



Have your say

healthwatch
Herefordshire

Are You a Carer?

We need to hear from you

Every day in the UK, someone is diagnosed with a disease or a condition. The treatment and support they will receive will, at some point, have been informed by **health & social care research**

Have your say about which studies & research gets done, how it's carried out & how it will benefit you, your family and your community

Share your views, opinions, experiences & ideas
Help us to improve the health of families in Herefordshire



Want to find out more?
text Mary on 07925 882537
Mary@healthwatchherefordshire.co.uk
www.healthwatchherefordshire.co.uk

Talk to us...

Get in touch or scan the QR code to complete our questionnaire online



Have your say

healthwatch
Herefordshire

Farming Communities
in Herefordshire

We need to hear from you

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Have your say about which studies & research gets done, how it's carried out & how it will benefit you and your community

Share your views, opinions, experiences & ideas
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healthwatch

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