

# Integrated Care Northamptonshire Engaging in Research Collaborative Project

March 2024



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## Introduction and Background

Integrated Care Northamptonshire (ICN) successfully bid and secured funding from NHS England and the Department of Health and Social Care in October 2023 for the delivery of a Research Engagement Network (REN) Project in Northamptonshire.

The aim of the REN project is also to work in partnership with voluntary, community, faith and social enterprise (VCFSE) organisations to engage under-represented groups and communities, such as under-served groups with protected characteristics as well as inclusion health groups, to improve participation in NHS research. The REN project aligns with both national and regional approaches to the community, for example as identified in the Core20PLUS5<sup>1</sup> Strategy which aims to reduce health inequalities, and in the Integrated Care Northamptonshire Community Engagement Framework and NHS Northamptonshire Integrated Care Board Five-Year Joint Forward Plan<sup>2</sup>.

The ICN wanted to better understand what the barriers to health and social care research are within Northamptonshire and asked Healthwatch North and West Northamptonshire for support and collaboration on this topic. To deliver this project, Healthwatch North and West Northamptonshire (HWNW) agreed to engage with the community through a survey and two focus groups which would help to gather key information from community members. The survey for residents in Northamptonshire was designed for anyone over the age of 11, as this would ensure that young people's voices could be captured as a part of the project.

HWNW worked with partners across the county to deliver this part of the project. This project consisted of a survey and two focus groups. For the two focus groups, we worked with two local service providers; Bridge and The Hope Centre. Bridge is a Substance Misuse Programme that supports

<sup>1</sup> <https://www.england.nhs.uk/about/equality/equality-hub/national-healthcare-inequalities-improvement-programme/core20plus5/>

<sup>2</sup> <https://www.icnorthamptonshire.org.uk/updates/icb-fiveyear-joint-forward-plan-now-published-10067/>

<sup>3</sup> <https://www.bridge-northants.org.uk/>

individuals within Northamptonshire, they support those experiencing substance misuse and who are in need of support and looking to recover<sup>3</sup>. Bridge recruits, trains and supervises volunteers who have had drug or alcohol issues, allowing for practical peer support from those who understand the challenges of substance misuse. The ability for our organisation to partner with Bridge for a focus group, allowed us access to individuals experiencing substance misuse challenges, so that their voices could be heard as a part of this research.

The Hope Centre is a local service that supports homeless individuals and individuals experiencing issues relating to hardship, including addiction, poor mental health and wellbeing within Northamptonshire<sup>4</sup>. These give support by offering access to food pantries, free meals, necessary care items and various types of support to help individuals re-settle. The ability for our organisation to partner with The Hope Centre for a focus group allowed us access to individuals experiencing homelessness and economic deprivation, so that their voices could be heard as a part of this research.

<sup>4</sup> <https://northamptonhopecentre.org.uk/how-we-help/homelessness/>

## Key Findings Discussion

Our findings from the survey and focus groups gave insight into the barriers and motivating factors that affect engagement in health and social care research.

Our findings from the survey and focus groups gave insight into the barriers and motivating factors that affect engagement in health and social care research. Between the focus groups held at Bridge and The Hope Centre and the survey, over 150 people shared their views with us about health and social care research and engagement. The survey captured additional demographics and questions, while the focus groups did not ask for many demographics and kept the questions limited, focusing on group discussion. Of the total participants for the survey, there is a large presence of young voices within the survey responses, with 32% of the participants being between the ages of 19–25 and 5% of the participants being between the ages of 11–18. There was also a spread of different ethnicities, with 65% from white backgrounds and 33% from BAME (black and other ethnic minorities).

Some key findings have been identified and numbered below:

1. The majority of survey participants said that it was important for them to take part in healthcare research.

With 93% of participants expressing that they felt some level of importance to engage in health and social care research, this indicates that there is a general understanding that participating in health and social care research may have positive impacts. Of the survey participants, only 7% or 10 people said that it was not at all important to take part in research. To try and understand why this may be, we took the survey results from participants who said it was not important and did a cross-analysis of their answers to the question that asked participants what would encourage them to take part. We found the answers were mostly focused on incentives and the time that a survey takes. Therefore we may conclude that ways to encourage those who do not feel getting involved in research is important might be done

through offering incentivised/paid research opportunities and offering surveys that are short and time-conscious.

2. Almost half of the participants were not sure that they had a role in research.

Of the survey participants, 47% were unsure whether they had a role in research and 29% felt that they did not have a role. This was a significant number of participants who were unsure or did not feel that they had a role in research. For those who did state that they felt they had a role in research, this was due to current jobs or courses of study as well as a pre-existing understanding of the importance of research and sharing one's opinions. For those who said no or were unsure, it is likely that they may not feel that they understand the purpose or importance of research.

3. Only 14% (20) of participants felt that they knew how to influence changes in health and social care.

Of the 20 participants who felt they knew how to influence change, they felt that this could be done through participation, patient involvement and co-production. Individuals felt that a positive impact could be made by getting involved in surveys and forums in the community. For the other 86% of participants who either did not know or were unsure, this indicates that there is more that can be done within the community to prove to people that participating in research and community co-production opportunities can bring change to health and social care services. This reflects that people may not know the purpose of research or the benefits that come from sharing views and information.

4. Over three-quarters of all respondents wanted social media to be used to give out information on changes that have been made as a result of research.

The use of social media was chosen to be the desired mode for individuals to be able to see the changes that were made as a result of the research done. It was discussed in the feedback that receiving an update about the outcome or impact of a survey or research



participation was important to participants. Therefore, it should be noted that sharing updates and results of research on social media platforms is important to ensure that participants feel valued for their contribution, and it allows for evidence of change to be seen in the wider community.

5. The main barriers that stop people from participating in health and social care research are that: participants do not know it is happening and that they do not know how to take part. Other key reasons given were that the research can be too long and participants do not think it will make a difference.

We addressed the barriers that exist and asked participants what may stop them from taking part in health and social care research, the main reason chosen was that 46% of participants did not know it was happening. This indicates that health and social care researchers may not be utilising the right channels and/or tools to inform the public about what research opportunities are available. 34% of participants said that not knowing how to take part in research would stop them from taking part in health and social care research. This shows that the research process may not be clear to potential participants and the ways the research is being offered may not be effective. A fifth of participants stated that the length of the research would stop them from taking part, indicating that there is a benefit in making surveys and other research tools easy to engage with and low in time commitment. A fifth of participants also stated that if they do not think their participation would make a difference and that this would stop them from taking part. Therefore, the researcher would benefit from ensuring the purpose of the research is clear and that the reasons are highlighted as to why participating can positively impact the service or topic at hand.

6. Only 6% of participants said that the type of research would influence what may be stopping them from engaging in health and social care research.

This finding concludes that the greater part of participants feel that the barriers that may stop them from engaging in health and social care research are the same for any other type of research.

7. When asked how participants might want to be involved in research in the future the main method chosen was surveys.

88% of participants chose surveys as the method they would most like to be involved in for future research. Under half of the participants also said they would like to be involved in focus groups. This is likely due to the ease and accessibility of surveys, as they can be accessed in person or digitally and can be completed by a participant without time constraints.

8. The majority of participants said that having someone from their local community supporting with health and social care research would encourage them to take part.

84 or (61%) of participants felt that having someone from their local community to support them with health and social care research would encourage them to take part. The reasons why people felt that someone from their community could be of benefit, was because people felt that they could trust them and could be supported by them. Participants felt that having someone from the community made them feel represented and that they could relate to the person providing the support because they came from the same local community. Participants felt that having someone available would be beneficial in helping them understand the research and that they would be a resource that could provide information. These findings indicate that the best approach to gathering feedback from a set area within the community, would be to gather the support of local community members who can engage with people within the community.

9. Participants felt the following would encourage them to take part in research:



- a. The offer of incentives for engaging in research
- b. Whether the subject is of interest or personal relevance
- c. The ability to understand the impact or to be able to see a change
- d. The ability to make a difference by taking part
- e. Having an understanding of the research's purpose and having clarity on the topic
- f. The research not being time-consuming and being easy to complete
- g. The need for more awareness/better publicity of research opportunities

From the two focus groups, key themes were identified around barriers of engagement, modes of encouragement for engagement and best methods of engagement. These focus groups include the voices of those who are homeless and who are battling substance and alcohol misuse. The key findings are detailed below in numbered order.

1. Participants felt that research and surveys need to be simplified to be easily accessible and appealing to the public for engagement.

Participants of the focus groups felt that they would be encouraged to engage in research and surveys if they were designed to be easy to use and approachable for all individuals. Stating that there would be benefit in a reduced use of jargon and use of simplified language. If research is designed in a way that is not easily understood by someone who is outside of the field, then participants may be hesitant to participate if they feel they do not understand the research.

2. Participants felt it was important to know the background, purpose and aims of the research when taking part.

Participants of the focus groups discussed the importance of understanding the research, as this is key to encouraging them to participate and a lack of understanding can be a barrier to research. Individuals highlighted that it is important to understand what the

research is about, so that they can make informed decisions. Knowing why the research is being done and what will happen with the information being collected helps participants to decide whether they want to take part and also influences the desire for participants to make a difference. This also applies to how their information would be utilised, as there was some concern from focus group members about what would be done with their information and data.

3. Participants felt it was important to be able to receive feedback or an update about the research after participating.

Participants spoke about the importance of knowing the outcomes of the research they took part in. Participants expressed that a lack of feedback after participating in the research was a concern, as was not having an understanding of who was conducting the research and why, which would cause a lack of trust. Focus group members expressed that they wanted to be able to see that their participation made a difference, so being able to have an update on the outcomes would support this. Some felt that by not having an update about the research, that the research may not be getting done or that their feedback and data could be used for negative purposes.

4. Participants said that having someone you trust to inform you about research is an important factor for engagement.

The focus group participants stated that having someone who they trust engage with them about research would be an important factor for their participation. Participants stated that being approached by an organisation rather than an individual felt impersonal and reduced their willingness to take part in research. By having someone trustworthy introduce a research opportunity, participants felt that they could erase many doubts about the research and they could use that individual as a support while completing the research.

## Recommendations

Based on the feedback from the participants, we have considered recommendations that can be made to Integrated Care Northamptonshire and other community services that are looking to develop and engage the community in health and social care research. The following are our recommendations:

### **1. Improving the approach for the promotion and publicity of research opportunities by increasing the use of social media.**

The most prevalent reason for not taking part in research was individuals not knowing that it was taking place. The creation of a publicity strategy as a standard element of the planning stage of all research projects would allow for effective strategies to be discussed and implemented before any research goes live. As social media was suggested as a popular way to receive research information and outcomes and the use of social media for the publicity of the research would help the opportunities reach more people, we recommend this as an approach as it would allow for it to reach a broader section of the community.

### **2. Ensuring the background, purpose and aims of the research are clear and easily understandable.**

Many participants noted that the lack of knowledge about the aims and impacts of research was a barrier to engagement. It may be useful for a simple outline of the research aims and the background purpose as to why the research is being conducted, to be included at the beginning of any surveys or research tools. This should also outline the areas of service delivery that could be improved or impacted because of the research.

Participants said that a barrier to taking part in research was a lack of information about who their information may be seen by, and which parts would be used. Presenting clear concise information stating who would have access to the information and how it would be anonymised should be included before all surveys etc., as this allows for participants to make an informed decision about their participation in the research. Incorporating information on who will see data and how it will be used should be incorporated into all publicity strategies.

### **3. There is great benefit in collaborating with local community members for support with research and eliminating barriers within communities.**

There was much discussion and feedback around the benefit of having local community members supporting with health and social care research. Participants expressed that they felt as though they could trust local community members and felt encouraged to take part in research if they were able to have their support and guidance. This would be beneficial as it would also allow for more feedback and engagement from the cohorts of individuals who are lesser heard, for example those who experience challenges like homelessness or those individuals who's first language is not English.

# Response from Integrated Care Northamptonshire

The outcomes and recommendations following the engagement undertaken by Healthwatch reflects the wider outcomes from sessions overseen by other VCSE organisations. The feedback and data collected, will be fundamental in shaping how we communicate with communities regarding research and wider engagement opportunities that will support us to improve outcomes and reduce inequality.

During this process key individuals have expressed an interest to become research champions, continuing to support the Northamptonshire system to undertake and deliver better research engagement. The training being developed is an exciting opportunity to ensure champions are supported to best fulfil their role and ensure consistency in our approach.

## Methods

For this project, Healthwatch North and West Northamptonshire collaborated with the ICN to identify key themes and data that needed to be gathered from the project and from this HWNW devised a survey and focus group questions based on what was needed from the working group that was set up by the ICN to work on this project. The survey and focus group questions were then piloted with Young Healthwatch Northamptonshire, to ensure that it would be accessible to young people as well as adults.

### Survey

For the survey various key themes were asked to be included as part of the research questions, they were:

- Do you know how to influence changes in health and social care?
- Do you think that you have a role in research?
- How important is it for you to take part in healthcare research?
- Where would you like to see the information about changes that have been made because of research?
- What would stop you from taking part in health and social care research and would this change if the type of research was different?
- What would encourage you to take part in research?
- How might you want to be involved in research in future?
- What kind of research would you like to see in your community?
- Would having someone from your local community supporting with health and social care research encourage you to take part and if so why?



The survey was available online and the team attended venues in Northamptonshire to engage with and encourage the public to participate in the survey. We attended locations within the community including: the University of Northampton, and Bewiched Coffee's locations in Kettering and Corby. This approach allowed us to be present in the community in various areas across Northamptonshire, and gave us the opportunity to explain the purpose of the survey in detail.



The survey ran for three weeks from the middle of February 2024 and we received a total of 139 responses.

To ensure that the survey could gather as much exposure and engagement from the public, Healthwatch West and North Northamptonshire ran an online campaign. The social media posts (see image to the right for an example) for this project were shared across HWNW main social media platforms including: Facebook, X (formally Twitter) and Instagram. The engagement statistics from those posts saw that over 330 people saw the post on Facebook, over 250 people saw the post on X and over 30 people saw the post on Instagram.



### Focus Groups

To engage members of the public who are often seldom heard, we worked with partners and held two focus groups, one for those that are homeless and one for people with an experience of drug and alcohol misuse. The

focus group method was utilised because it allowed for us to connect with the participants on a personal level, allowing for reflection, group discussion and the collection of quantitative data. Individuals were able to provide their opinions in a safe and confidential environment supported by their peers.

Each focus group was led by a member of our HWNW team, who started the session by introducing the purpose of this research project and the consequent partnership of the Integrated Care Northamptonshire and Healthwatch North and West Northamptonshire. Participants were asked for their ages, but for the purpose of this research were not asked any further demographics of genders or ethnicities. This was to ensure that those who participated in our focus groups could not be identified, as those who access both Bridge and the Hope Centre are vulnerable groups that prioritise anonymity.

In the focus groups, participants had discussions around 5 key questions/ topics which were as follows:

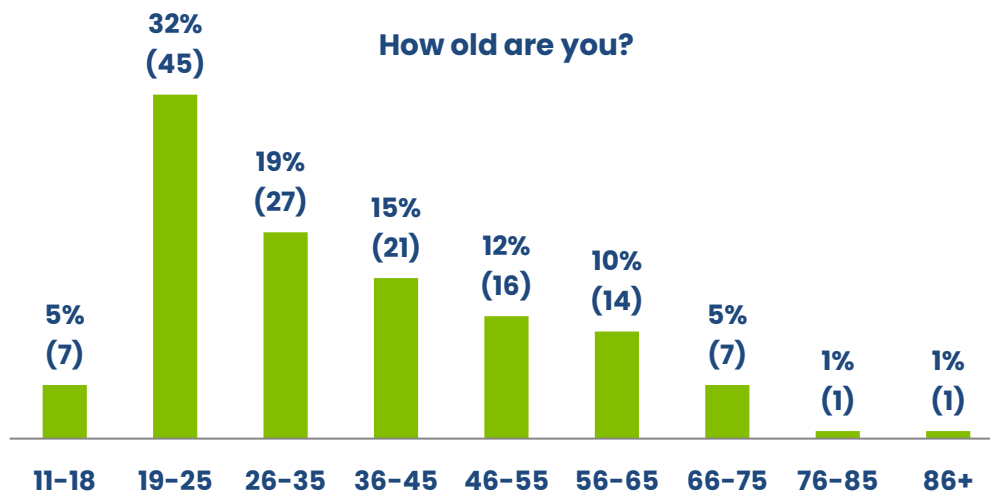
- If you could think of one thing that would encourage you to take part in research what would that be?
- Does anything concern you about taking part in research?
- Do you feel that research relates/means anything to you?
- How would you like researchers to ask you about your experiences?
- Would you like to be told about research by someone you trust?

It was explained that all answers would be kept anonymous and that the focus group participation and demographic questions were voluntary, and they could choose not to answer a question if they wished.

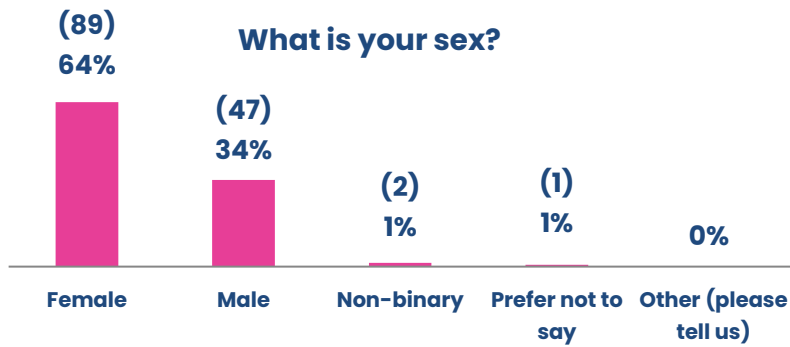
# Key Data and Results of Survey

## Demographics

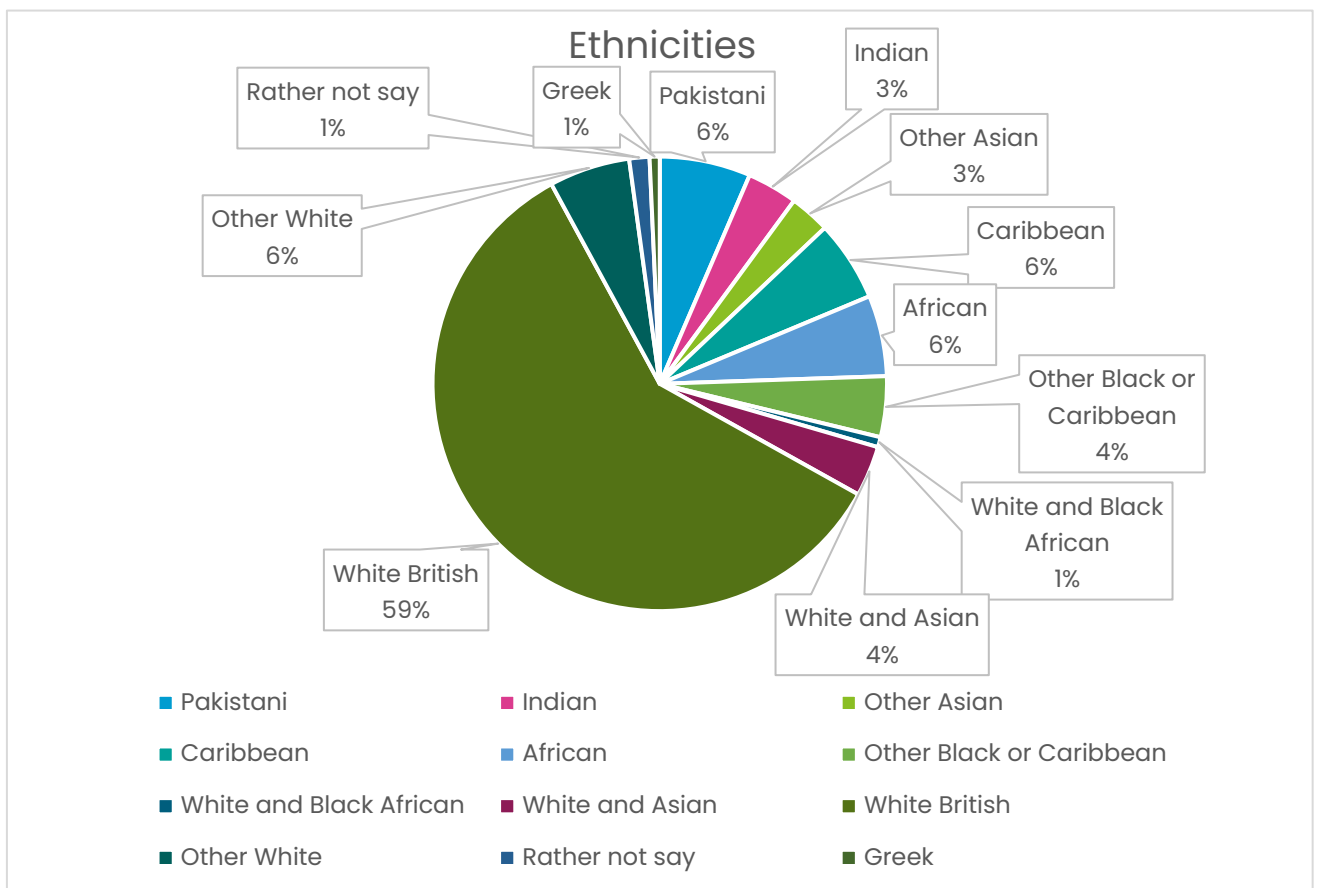
As a part of this research project, participants were asked to fill out demographic information, of the 139 participants the majority chose to take part in these questions. We asked participants these questions because it helps give insight into the individuals taking part, and allows for us to highlight certain areas of importance as we analyse the data gathered. Participants were asked about their ages and all of the 139 participants chose to answer this question. Over half of the participant's ages fell between the ages of 19 and 35, with 32% being between 19 and 25 and 5% being between 11 and 18. This data concludes that there was increased engagement and a strong presence of views from children and young people within the survey. It is also worth noting that 93% of all respondents were considered working age.



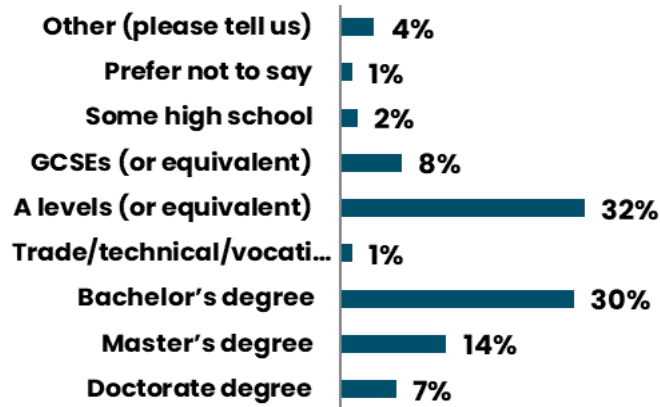
We asked participants to identify what gender they were and all 139 participants chose to respond to the question. The majority of respondents identified as female (64%) and 34% identified as male. Two of the respondents were non-binary and one respondent chose not to say.



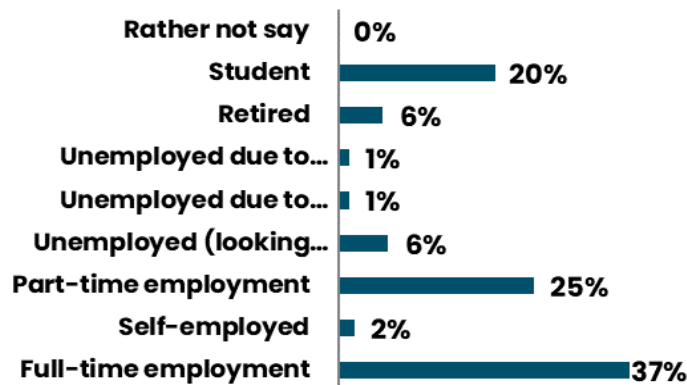
We asked participants to identify their ethnicities and all 139 participants chose to answer this question. We found that 59% of participants were White British, and the other 41% were a mix of different ethnicities. The ranges of different ethnicities present allows for the survey to have diversity and this is significant, as it means the voices heard from within the survey are from different backgrounds and ethnicities.



We asked participants about their education and highest level of qualification, all 139 participants chose to answer this question. A little over half of the participants stated they had a bachelor's degree or higher, approximately a third of the participants had A-levels or equivalent, and the remainder of participants had GCSEs or equivalent, some high school, trade school or preferred not to say.

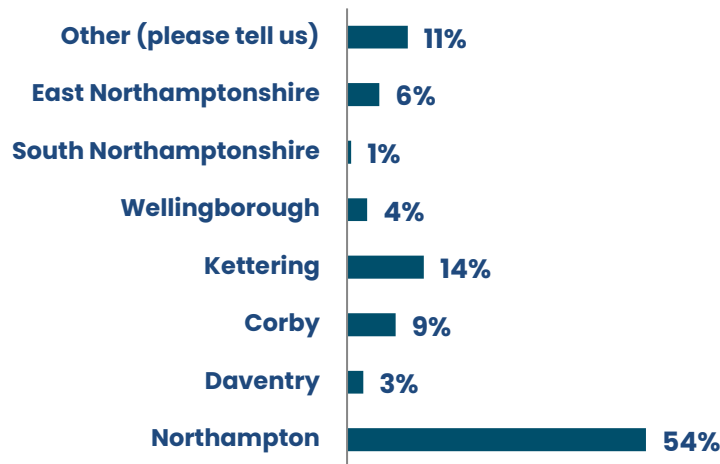


We asked participants about their employment status and we found that the majority were either in part-time or full-time employment. A fifth of participants were students, and a small percentage were either retired, unemployed and looking for work, unemployed due to caring responsibilities or unemployed due to illness or disability.



We asked participants where they were located within Northamptonshire and we found that 89% of participants were located within Northamptonshire, and 11% were not. Of those within Northamptonshire the majority were within Northampton town. The 11% that stated that they do

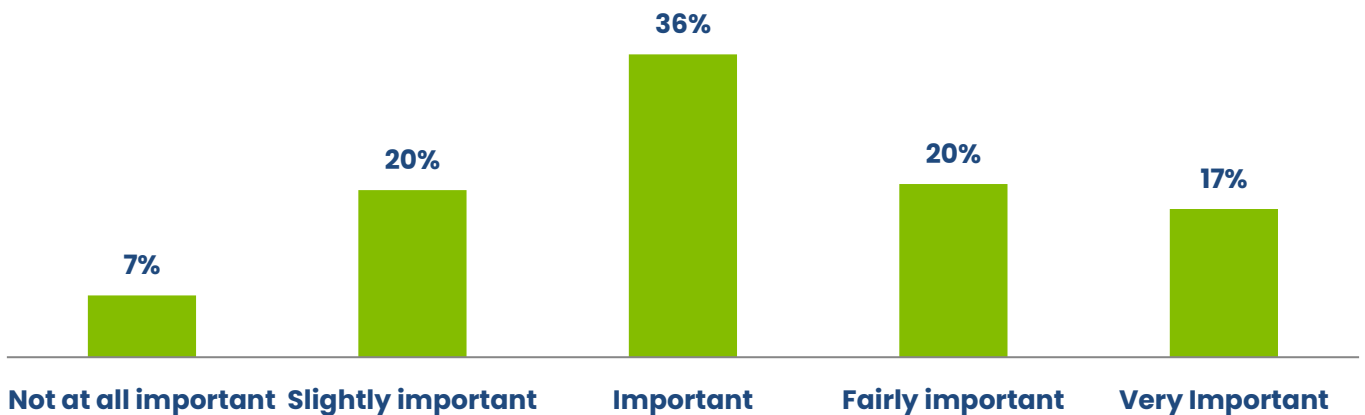
not live within Northamptonshire may be due to many of the participants being students at the University of Northampton, through cross analysis we identified that 6 participants which stated they lived outside of Northamptonshire were students and therefore may not have considered their home residence to be within Northamptonshire.



### Participant Views on Research

We asked participants how important it is for them to take part in healthcare research, 138 participants chose to answer this question.

How important is it for you to take part in healthcare research?



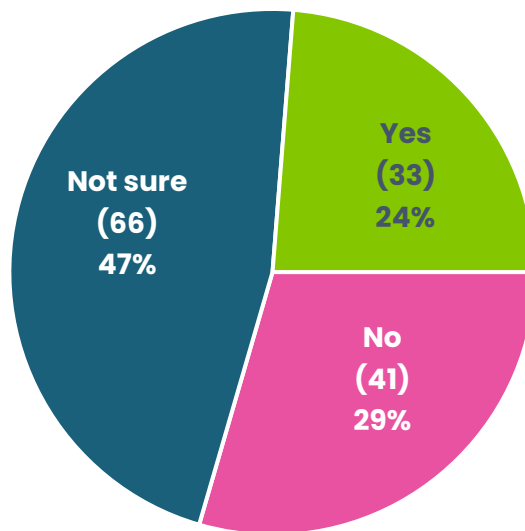
We found that the majority of participants did find it important, with 17% stating that it was very important, and 93% of the participants found it to be at least slightly important. Of the 7% which did not find it to be important at all, we decided to cross analyse this data with the data gathered about



educational qualifications. We found that of the 10 participants who felt that taking part in healthcare research was not important, 2 of the participants had doctorate degrees, 2 participants had bachelors degrees, and the remaining 6 participants had A levels or equivalent.

We asked participants if they felt they had a role in research, all 139 participants chose to answer this question. 47% said they were unsure if they had a role in research, 29% did not feel that they had a role in

**Do you think that you have a role in research?**

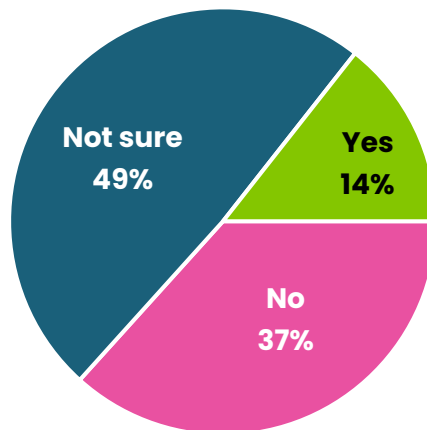


research and 24% felt that they did have a role in research.

Of those who felt that they had a role in research, 64% had a qualification of a bachelors degree or higher. For those who chose yes and felt they had a role in research, they were allotted a free text box to expand on their answer. Participants feedback into the free text box and their answers were analysed for commonalities and themes, many individuals stated that research was apart of their current job or part of their current course of study. Other feedback received was that having an idea or opinion is important to share for research and contributing experiences is important if you want to change services.

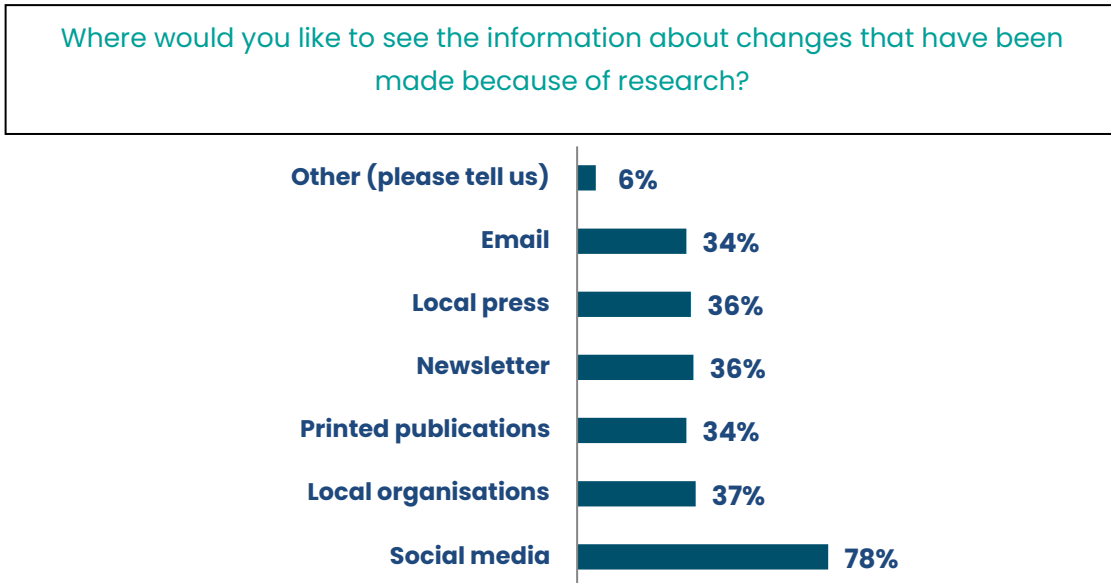
We asked participants if they knew how to influence changes in health and social care. All participants chose to answer this question, with just under half (49%) of individuals reflecting that they were unsure of how to influence changes in health and social care, 37% of participants did not know how to influence changes in health and social care and 14% felt that they did know how to influence changes. Those who stated that they did feel that they knew how to influence change were offered a free text box to expand on their choice, and all 20 individuals provided feedback. Participants answers were analysed for commonalities and themes, many individuals stated this could be done through participation, patient involvement and coproduction, and that there is impact in getting involved in surveys and forums in the community.

**Do you know how to influence changes in health and social care?**



## Engaging in Research

We asked participants where they would like to see the information about changes that have been made because of research. Of the 139 participants, 1 chose to skip this question. Participants were provided with a



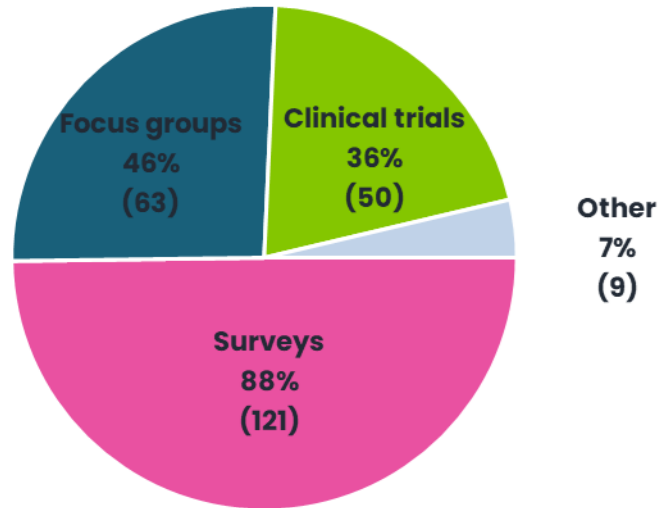
list of different media and were able to select multiple options for this question.

The majority of participants stated that they would like to see information shared about changes that have been made due to research outcomes shared through social media. Other methods which would be favoured by approximately a third of participants included: local organisations, printed publications, newsletters, local press and email. Those who selected other stated that all of the options would be beneficial, as well as suggesting that news sites share the information.

Participants were asked how they would want to be involved in research in the future, individuals were able to select more than one answer for this question, and all but one participant chose to answer. The main method was through surveys, with 88% of participants choosing this option. Just under half of participants would want to be involved in focus groups and 36% in clinical trials. 9 participants chose to share other methods, some of

which were: not wanting to be involved in research, consultations and longitudinal studies.

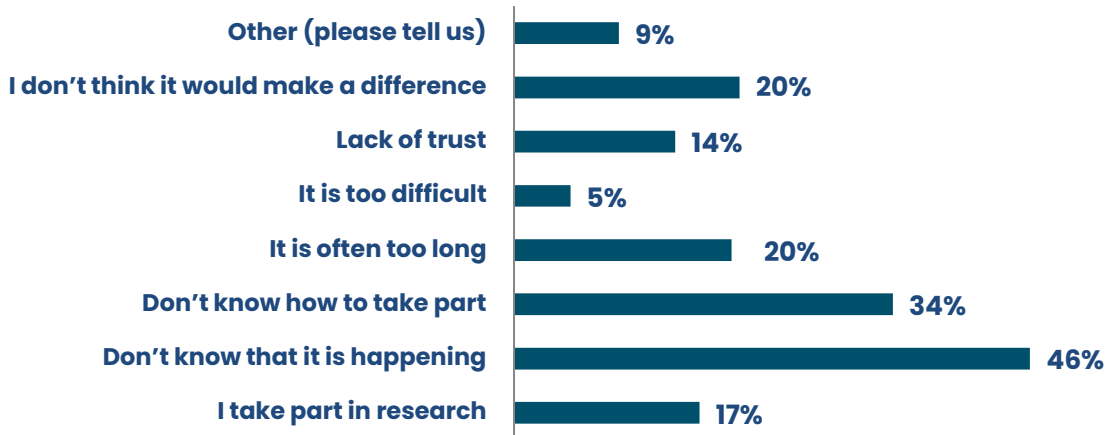
**How might you want to be involved in research in future?**



## Barriers to Research

We asked participants if there was anything that was stopping them from taking part in health and social care research. 138 out of 139 participants chose to answer this question. Participants were able to select all options that applied. The main reason that stops individuals from taking part in research was that they did not know it was happening. A third of individuals stated that if they did not know how to take part in health and social care research, that this would stop them from taking part. 20% of participants stated that they did not think it would make a difference and 20% of participants thought that it is often too long.

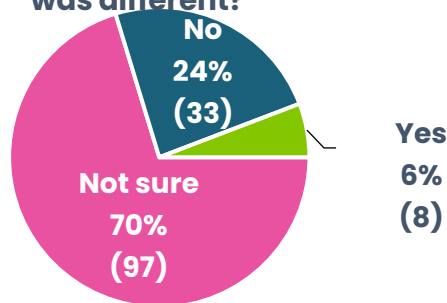
What would stop you from taking part in health and social care research?



14% of participants stated that a lack of trust would stop them in taking part in health and social care research. We wanted to identify which ages and ethnic groups felt that lack of trust was a reason to not engage in research, we found that of the 20 participants who chose this answer, 55% were between 19-25. Of the ethnic groups who chose this answer, 55% were White British and 45% were Black and Ethnic Minorities. Those participants who chose "Other" as an option were given the opportunity to provide their answers in free text, which were analysed for key themes. Participants stated that barriers may be things such as

We asked participants whether what may stop them participating in research would change if the type of research was different, only 6% of participants said that this would change based on the topic of the research. Approximately a fourth of participants did not feel that their engagement would change if the topic was different. The majority of participants were unsure of their views on this question.

**Would this change if the type of research was different?**



Participants were asked what would encourage them to take part in research, this question was provided with a free text box, so that participants could openly express their views. Of the 139 participants, 131 chose to provide answers to this question. Through analysis of the responses, individual replies were placed within key themes that were identified for modes of encouragement, these were as follows:

10. The offer of incentives to engage
11. Whether the subject is of interest or personal relevance
12. The ability to understand the impact or to be able to see change
13. The ability to make a difference by taking part
14. Having an understanding of the research's purpose and having clarity on the topic
15. The research not being time consuming and being easy to complete
16. The need for more awareness/better publicity of research opportunities
17. Miscellaneous

When participants expressed how incentives would encourage them to take part in research, participants frequently said that money was an incentive with 11% of those who responded sharing this sentiment. Incentives besides money that were discussed were things like vouchers, freebies and educational credit. Participant voices were captured, two of which are worth highlighting:

- "If it was paid or it was something that I was well informed of and passionate about."
- "A voucher or some incentive always helps with the way everyone is struggling."

11% of participants expressed the importance of whether the subject is of interest or personal relevance as the factor that would encourage them to take part in research. Participants said that they wanted to engage with research in a subject that they had interest and experience in, and whether that topic affected them or their families influenced whether they engaged in research. Participant voices were captured, two of which are worth highlighting:



- “If it was linked to a personal experience or there was evidence of prior similar research having made a positive impact.”
- “If it relates to a specific topic that I find interesting.”

18% of participants expressed the importance of whether they could understand the impact and see the change as the factor that would encourage them to take part in research. Participants said that it was important for them to be able to see the change or future change relating to the topic of research, as well as needing to feel that they understand what is being researched and what the research’s outcomes and impact will be. Participants also stated that it is important to know how they are using their information and how their feedback would affect the topic. Participant voices were captured, a few of which are worth highlighting:

- “Knowing what the outcome would be and how the feedback would be used.”
- “Knowing when and why the research is taking place.”
- “Understanding of the planned outcomes, what next from the results.”

6% of participants expressed the importance of whether they could make a difference as the factor that would encourage them to take part in research. Participants frequently said that it was important for them to be able to feel as though they could make a difference in the topic being researched and whether their involvement in research would impact society positively. Participant voices were captured, a few of which are worth highlighting:

- “If I feel it will add value to society.”
- “Feeling like it is relevant and that I can make a difference.”

13% of participants expressed the importance of having an understanding of the research’s purpose and having clarity on the topic as the factor that would encourage them to take part in research. Participants frequently said that it was important for them to ensure that they knew the aims and purpose of the research as well as what the outcomes and what all the

research entails. Participant voices were captured, a few statements are worth highlighting:

- “Clearly defined aims, information about the ethical review of the research study, looks professional, a topic that is of importance to me, my family, friends.”
- “Understanding what the research would involve.”
- “If we knew about what the aim of the research was.”

9% of participants expressed the importance of the research not being time consuming and being easy to complete as the factor that would encourage them to take part in research. Participants said that they would be inclined to engage in research if the research was easy to access and not time consuming, taking as little time as possible. Participant voices were captured, with a few statements worth highlighting:

- “If it doesn’t take a long time, get very discouraged if it’s takes more time than needed since I never feel like I have enough time in my life.”
- “If it was easy and not time consuming.”

12% of participants expressed the importance of research opportunities having better publicity as the factor that would encourage them to take part in research. Participants highlighted the importance of research opportunities having better publicity with the issue being raised that more advertisement needs to be done promoting studies that are relevant to their demographics and not feeling as though they are aware of opportunities. It was mentioned that if more awareness was done and if the research was promoted effectively on social media, that this would benefit engagement. Participant voices were captured, with a few statements worth highlighting:

- “More advertisement for studies that are relevant to my demographic.”
- “Wider communication of the research opportunities available.”

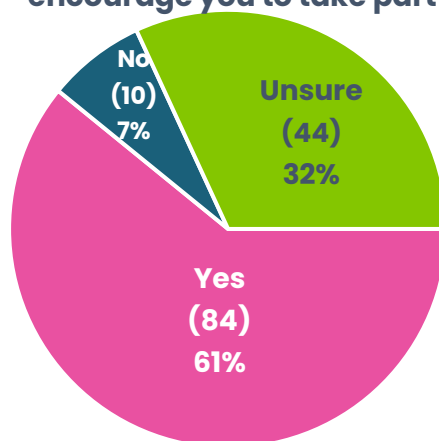
5% of participants were unsure of an answer to what would encourage them to take part in research.

15% of participants provided answers which did not fit within the identified themes and were deemed miscellaneous. Of the miscellaneous answers provided by participants a few things were discussed such as: the importance of the research they would engage with being directly tied to the government’s health department, knowing that the research would not have an impact on the participant’s mental health and wellbeing, engaging with research specifically focused on mental health, and that participants are already motivated to engage and do not have any factors that would help them to engage.

### Community Support

Participants were asked if having someone from their local community supporting with health and social care research would encourage them to take part in research. Out of the total participants only one chose to skip this question. The majority (61%) of participants said yes, that this would encourage them to engage in research if they had the support of an individual from the local community involved in the health and social care research. 7% said that this would not encourage them to take part in research and 32% of participants were unsure whether this would encourage them to take part.

**Would having someone from your local community supporting with health and social care research encourage you to take part?**



Participants were then given a free text box and asked why they answered either yes, unsure, or no when asked if having someone from their local

community supporting health and social care research would encourage them to take part. Of the total participants, 121 responded out of 139. Through the analysis of the responses, individual responses were placed within key themes that were identified as reasons why having an individual from their local community supporting health and social care research would encourage or discourage their participation. These themes were as follows:

- Trust
- Representation/Relatedness
- Ability to provide information/ having someone who is informed
- Support
- Having Clarity

Trust was discussed as something which would need to be developed with the individual from their local community who was supporting the health and social care research. Participants expressed that having someone there to trust would give them assurance and confidence to participate in research. One participant said, "I feel like I would trust the research more and would be up to being more involved."

Participants thought that having someone from their local community supporting health and social care research would encourage them to take part, because of the representation and shared experience that the person would have.

Participants said:

- "It always helps when you feel you have someone in your corner from the same area/ community background."
- "Because it would be nice to have a voice from our community, helping educate everybody on how to make a difference."

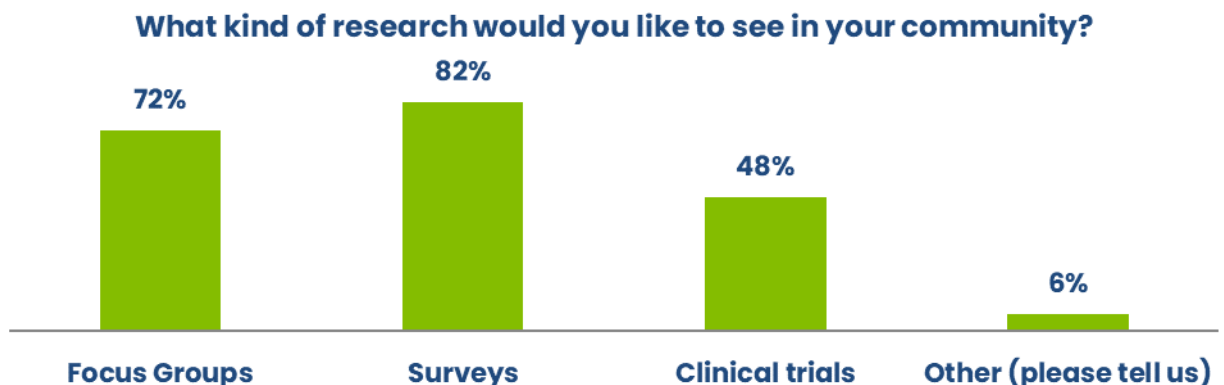
Participants felt that there would be great benefit in having someone from the community to support with health and social care research because they would be informed about the research and could provide guidance

and explain the research. Participants felt that if someone was present who could explain more about the type of research and how it would help the greater good, that they would be more likely to want to engage and would feel supported taking part.

Participants said:

- “Help to explain what’s happening and how it affects everyone.”
- “As they would be able to tell me what the research is for and about.”
- “Would help my confidence and make me feel like I had a better chance of being listened to and taken seriously.”
- “Because then I would know a little more about the type of research available to partake in.”

We asked participants what kind of research they would like to see in their community, all but one participant chose to answer this question and participants were able to select more than one answer. 82% of participants (113) stated that they would like to see surveys used and 72% of participants said they would like to see focus groups used. Just under half of the respondents said they would like to see clinical trials. Of the participants who chose other, feedback for this mostly stated “anything that is relevant”, a few other participants stated that they wanted to see the focus of research to be about the neighbourhood they are in and for community groups to be used as a support for research.



### Focus groups

We conducted 2 focus groups with local community organisations that support groups of individuals who typically experience health inequalities. The first focus group took place at the Hope Centre in Northampton and

was attended by people who were accessing the service for the homeless that day. The 6 participants were aged between 27 years old and 62 years old. The second focus group took place at Bridge in Northampton and was attended by a mixture of staff, volunteers and service users. There were a further six participants that took part and their ages ranged from 38 years old to 67 years old. Due to the nature of both of these services, we did not collect demographic information from the participants, apart from their age as we did not want them to be identifiable.

We asked both groups the same 5 questions:

- 1) If you could think of one thing that would encourage you to take part in research what would that be?
- 2) Does anything concern you about taking part in research?
- 3) Do you feel that research relates/means anything to you?
- 4) How would you like researchers to ask you about your experiences?
- 5) Would you like to be told about research by someone you trust?

The groups shared their ideas and opinions out loud in the group setting, and their responses were captured. We then qualitatively analysed the responses and created themes as well as highlighted some statements from participants.

### Bridge Focus Group

At Bridge when the participants were asked if they could think of one thing that would encourage them to take part in research they gave a variety of responses. Many of the individuals felt that they would feel encouraged if there was a reduced use of jargon and the use of simplified language, this would make the survey more approachable. Similarly, one participant felt that a reduction in the amount of text used would increase their interest in taking part. They expressed that there would be a benefit in ensuring that relevant questions were used and if surveys could ask the least amount of questions. Participants also stated that being able to see the change in services because of the research would be encouraging to them. Survey

fatigue was also discussed, as individuals felt that sometimes there are too many surveys and that they felt as though they were always being asked.

When the participants were asked if anything concerned them about taking part in research, the focus was on their data and the lack of feedback after participating. Concerns were about the possible security and privacy implications of sharing information when they were not clear on where it would go. Participants expressed that a lack of feedback after participating in the research was a concern, as was not having an understanding of who was conducting the research and why, causing a lack of trust. A quote from a participant expressing their concerns was “Am I just making someone else look like they are good at their job?”

Participants thought that research could relate or mean something to them if it was relevant to their experience, was a topic interesting to them and they were able to receive feedback on the results. The issue of using plain language and making reasonable adjustments to accommodate difficulties and differences was again raised in response to the question.

Participants said that the best methods for how they would like to be asked about their experiences concerning the research was to have face-to-face conversations, focus groups and online conversations with researchers. Researchers coming to the individuals to conduct research, in a place that they felt safe and comfortable was also a priority. The group felt that receiving physical surveys through the post would help to overcome barriers to using technology such as age, learning disabilities lack of access to computers.

Participants at Bridge felt that being told about research by someone they trusted was important, as there was already a level of trust developed and that the familiarity made it easier to open up. They felt that being approached by an organisation rather than an individual felt impersonal and reduced their willingness to take part in research.

### The Hope Centre

At The Hope Centre focus group, the first question of what would encourage participation in research received the most feedback from

participants. The participants highlighted the importance of knowing the aims of the research, of being able to see how the research was being used and its implications and impacts on services as things that would encourage participation. The group offered practical suggestions of ways research could encourage participation, such as; offering surveys etc in other languages, creating a video to explain the purpose of the research you were looking to recruit participants for and giving participants the date that the results were expected to be published so they could see the results.

The use of incentives such as money or vouchers was suggested as a way to encourage participation, but the group noted that this may vary in usefulness depending on an individual's circumstances. Participants said that if research was connected to a topic they had experience with or were interested in that this would encourage them to take part. They noted that sometimes an attitude of professionalism rather than friendliness could be a barrier. Participants expressed that not feeling like they were being listened to could discourage participation. Participants thought that using staff who had been trained to engage with service users and who approached them in a compassionate manner could overcome this.

When participants were asked about their concerns around taking part in research, the responses focused on the concern that research is not actually being completed. This was a concern because participants felt that they had never seen feedback or updates from previous research they had engaged with. A concern was shared over the worry that the research could be used to create fear in the general population. Other group members mentioned the possible time factor in completing a lengthy questionnaire, "It should take the time it takes. If it says 1 minute, it should take 1 minute."

The group at The Hope Centre felt that research was only related or meant anything to them if it was linked to a topic which impacted them personally.

When asked how they would like researchers to ask them about their experiences, group members thought that online or in-person focus



groups which came to the service they were using would be the preference.

When participants were asked if they would like to be told about research by someone they trusted, the group felt that information being provided by a trusted person would mean more than information that was given by someone whom they had no connection to. The group felt that the environment that the research took place was an important factor, stating that having too much noise or being within a very busy environment would make it difficult for some people to take part in research.

## Acknowledgements

Healthwatch North and West Northamptonshire would like to thank all of the individuals who took the time to engage with us and participate in this research, that was done in collaboration with Integrated Care Northamptonshire. Thank you to the University of Northampton and Bewitched Coffee for the use of their facilities to engage with members of the public. Thank you to Bridge and The Hope Centre for your collaboration and ability for us to work with your services to hold focus groups and connect with your service users.

# About Healthwatch North and West Northamptonshire

Healthwatch North and West the NHS and social care, and the Care Quality Commission (CQC) (the inspector and regulator for health and social care), with recommendations for improvement, where required.

Our rights and responsibilities include:

- We have the power to monitor (known as “Enter and View”) health and social care services (with one or two exceptions). Our primary purpose is to find out what patients, service users, carers and the wider public think of health and social care.
- We report our findings of local views and experiences to health and social care decision makers and make the case for improved services where we find there is a need for improvement
- We strive to be a strong and powerful voice for local people, to influence how services are planned, organised and delivered.
- We aim to be an effective voice rooted in the community. To be that voice, we find out what local people think about health and social care. We research patient, user and carer opinions using lots of different ways of finding out views and experiences. We do this to give local people a voice. We provide information and advice about health and social care services.

Where we feel that the views and voices of Healthwatch North and West Northamptonshire and the people who we strive to speak on behalf of are not being heard, we have the option to escalate our concerns and report our evidence to national organisations including Healthwatch England, NHS England and the Care Quality Commission.

**Find out more at [www.healthwatchnorthamptonshire.co.uk](http://www.healthwatchnorthamptonshire.co.uk)**



## About Connected Together

**Connected Together Community Interest Company (CIC) is the legal entity and governing body for Healthwatch North and West Northamptonshire.**

The remit of the Connected Together CIC includes:

- Contract compliance
- Legal requirements
- Financial and risk management
- Sustainability and growth
- Agreeing strategy and operations
- Agreeing policies and procedures



Connected Together CIC is a social enterprise and a partnership between the University of Northampton and Voluntary Impact Northamptonshire. It aims to be first for community engagement across the county of Northamptonshire and beyond.

By using our expertise and experience, we can help you in delivering community engagement programmes including workshops, research, surveys, training and more. Contact us to find out how we can help your community.

We welcome ideas and suggestions for projects that benefit Northamptonshire and its community.

**Find out more at [www.connectedtogether.co.uk](http://www.connectedtogether.co.uk)**



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