Engaging underrepresented people in a regional transformation project: co-production of a framework

Lancaster University

Lancashire & South Cumbria New Hospitals Programme

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Foreword

Our starting point for this project was to co-produce a best practice framework to facilitate engagement with underrepresented groups in the Lancashire and South Cumbria New Hospitals Programme. As a regional transformation project that will impact on future generations of citizens, the importance of engaging with a wide range of views and opinions to shape plans and ambitions is critical. The more people know about the New Hospitals Programme, the greater benefit there will be to those who will use its services in the future.

The co-production approach we used meant that there were opportunities to share as we journeyed through the project which provided the chance to incorporate learnings in real-time into the New Hospitals Programme's approach. We were also able to engage with a wider group of people to test out ideas as they were developing. The outputs of this project provide the New Hospitals Programme with a framework to hear from a much wider range of people and perspectives, which we hope will lead to better decisions.

The findings from this project could also have a wider benefit. As the new Integrated Care System (ICS) becomes established, the framework developed in this project is equally as relevant and transferrable to the engagement activities of all partners within the health and care system. We also hope that the learnings from this project could influence the approach to engagement undertaken in other New Hospital Programme schemes across the county (Improving NHS Infrastructure).

As we continue to learn about engaging with those from underrepresented groups, the framework we share in this report will develop and mature. We would be interested to hear from others who use the framework and in particular welcome feedback on how useful you find it, and ideas about how you think it could be improved.

To share your thoughts, please email the New Hospitals Programme team at LSCNHP@lthtr.nhs.uk.

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Executive Summary

This report summarises the activities from the *Engaging Underrepresented People in a Regional Transformation Project*, a collaboration with the Lancashire and South Cumbria New Hospitals Programme (LSCNHP). The project was awarded project funding from Research England through the Lancaster University Vice-Chancellor's Prize for Participatory Research. The project ran from the beginning of March to the end of July 2022.

The Lancashire and South Cumbria New Hospitals Programme is part of the Government's commitment to building 40 new hospitals by 2030. Together with eight existing schemes, this will mean 48 hospitals built in England over the next decade, the biggest hospital building programme in a generation. Find out more on the 'Improving NHS infrastructure' website.

Discussions with the New Hospitals Programme team identified that, whilst there has been engagement with regional stakeholders, local people, patients, staff, and some health inclusion groups, there was still a gap in the engagement of those who were routinely underrepresented. The project team were open to further insight and suggestions on how to address the gap. This project aimed to:

• Fill a gap in knowledge on good practice engagement with underrepresented people,

• Produce a framework for future engagement practice,

• Provide evidence to inform the New Hospitals Programme's engagement practice,

• Inform engagement approaches for future transformation projects.

The Director of the New Hospitals Programme, Rebecca Malin, and the programme's communications and engagement team were actively involved in this project, actively participating in the co-production of the framework for engagement with underrepresented people. Several conversations with a stakeholder group made up of representatives from a range of local NHS organisations, including all the local NHS Trusts, Central Lancashire and Morecambe Bay Clinical Commissioning Groups (CCGs), and the Integrated Care System and Healthwatch also shaped the resultant framework.

From the evidence review and regular discussions with the New Hospitals Programme, the co-produced framework highlighted how the New Hospitals Programme could move towards active collaboration with underrepresented people. The New Hospitals Programme's current engagement practice has been mapped using the framework and has been used by the team to indicate future action plans to build on and improve their practice.

The anticipated benefits of the project include an improved approach to engagement with underrepresented people and the wider community through the New Hospitals Programme, as well as learnings that could be transferred to the national New Hospital Programme. It is anticipated that specific changes to engagement practice will be made in areas including accessibility, engagement mechanisms and activities and meaningful feedback following engagement. Furthermore, there is the opportunity for the learnings captured from this project to inform the engagement approach of other transformation programmes.

This project has served to consolidate the relationship that we have with the Lancashire and South Cumbria New Hospitals Programme, which provides the platform for a planned series of workshops to develop a research project pipeline. These workshops will bring together academics from across disciplines at Lancaster University with colleagues in the New Hospitals Programme, Trusts and wider NHS to develop fundable research areas and questions on the theme of Sustainability.

Themes from the Framework

Short descriptions of the themes from the framework (described in more detail on pages 24 - 63).

Values and Principles

The values and principles that underpin and guide the organisation's approach to meaningful engagement with underrepresented people.

Trust

Building and maintaining trust between underrepresented people, engagement practitioners and organisations is critical.

Diversity and Inclusion

Respecting and valuing all forms of difference in individuals, striving to meet the needs of different people and taking deliberate action to create environments where everyone feels respected and able to achieve their full potential.

Level of involvement

Considerations for the range of ways that people from underrepresented groups can be involved in the different stages of planning and delivering engagement and associated projects.

Listening and Providing Feedback

Many underrepresented people do not trust that organisations will genuinely listen to their ideas and views, therefore it is important that organisations demonstrate how they have listened and what has happened as a result.

Drawing on and incorporating local knowledge

Drawing on and incorporating local knowledge and assets to ensure that new services or designs for a specific location reflect the local context.

Learning and Capacity Building

Considerations for creating a collaborative culture through learning and capacity building. Within the evidence base, mutual learning between both staff and participants is highlighted as central to effective engagement processes.

Resources

This includes considerations for time, funding, materials, staff, and other resources that support engagement activities with underrepresented people.

Beyond Traditional Methods

A diverse range of engagement approaches enables equality of opportunity within participatory activities.

Accessibility

Providing people with the equal opportunity to participate fully and finding ways to remove barriers to communication materials and participating in engagement activities.

Tailoring and Combining

Using a variety of different methods helps reach diverse groups of people with different communication preferences. One size does not fit all.

Sustainability

The progression of engagement beyond one-off, discrete activities, to ongoing processes where underrepresented people are listened to and enabled to influence change within services and organisations.

The New Hospitals Programme Engagement Wheel

As part of this project, an engagement wheel to guide future engagement with underrepresented people was co-designed. The wheel is based on the IAP2 Spectrum for Engagement (2018).
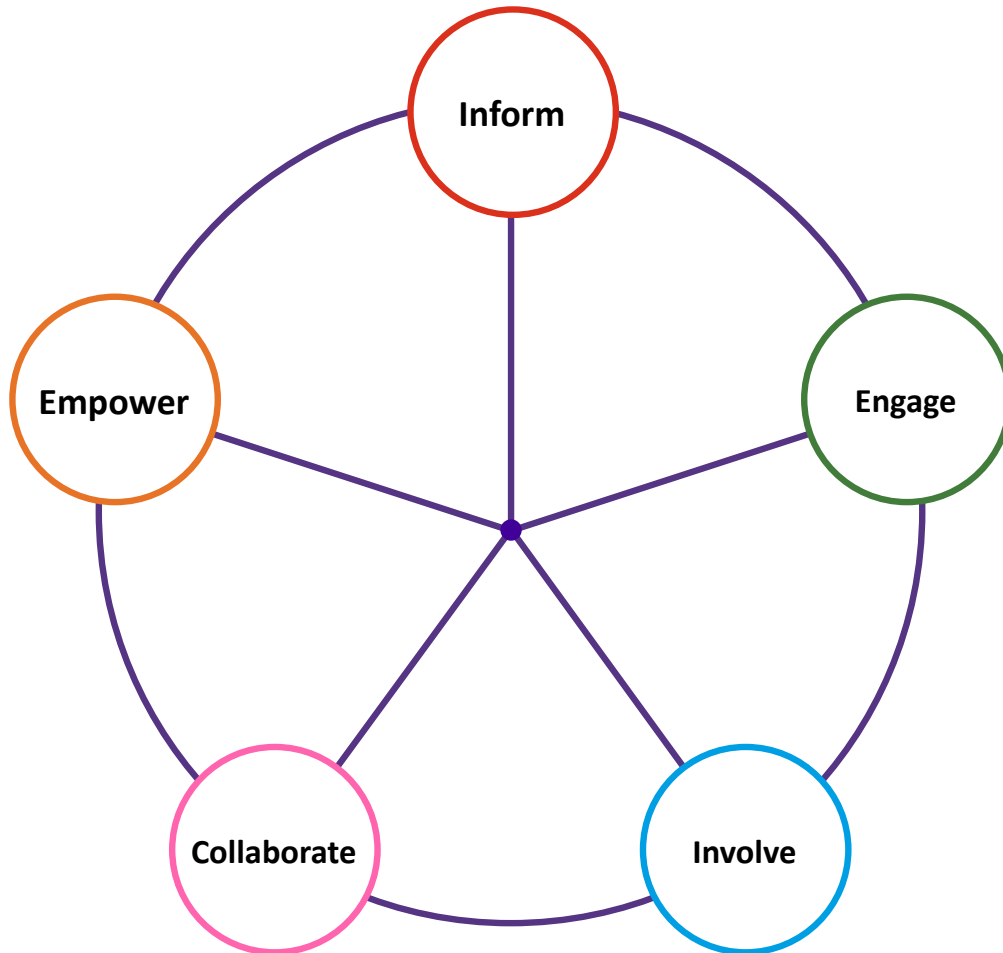
○ **Inform** - To inform the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.

○ **Engage** - To obtain public feedback on alternatives and/or decisions.

○ **Involve** - To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.

○ **Collaborate** - To partner with the public in each aspect of the decision, including the development of alternatives and the identification of the preferred solution.

○ **Empower** - To place final decision-making in the hands of the public.

Introduction

In early 2022, a team from Lancaster University's Faculty of Health and Medicine and the Lancashire and South Cumbria New Hospitals Programme (LSCNHP) were awarded project funding from the Lancaster University Vice-Chancellor's Prize for Participatory Research through Research England. The aim of the collaborative project was to fill the gap in knowledge on best practices of how to engage underrepresented people and provide evidence to inform engagement approaches that might be useful for future transformation projects.

The Lancashire and South Cumbria New Hospitals Programme (LSCNHP) is a once-in-a-generation opportunity to transform hospitals and the healthcare system in Preston and Lancaster, with investment into Furness General Hospitals' infrastructure. The LSCNHP aims to create a network of brand-new and refurbished facilities, help local people live longer, healthier lives and make Lancashire and South Cumbria a world-leading centre of excellence for hospital care. This fits within the government's national scheme to build 40 hospitals by 2030, the largest hospital building programme in a generation. The new hospitals aim to provide better care for patients, an improved working environment for staff and help the NHS reach the net zero carbon ambition (DHSC, 2021).

The success of the programme will be dependent on meaningful stakeholder engagement in shaping plans and ambitions. Discussions with the New Hospitals Programme team identified that whilst there has been engagement with regional stakeholders, there is a gap in the engagement of those who are routinely underrepresented.

The project objectives for the participatory research project were as follows:

• Set up a stakeholder engagement group, including those routinely underrepresented to be partners in the whole research cycle.

• Map current engagement mechanisms being used in the LSCNHP and national New Hospital Programme against existing evidence relating to engaging with those from underrepresented groups.

• Co-create a participatory approach for engagement in regional transformation projects.

• Pilot approach and refine it based on findings.

• Finalise the approach, and draw out transferable lessons, principles, and mechanisms for other transformation projects such as Health Innovation at Lancaster and Eden Project North.

• Using this project's co-creation process to agree research questions for future large-scale funding.

Engaging with Underrepresented People

The Lancashire and South Cumbria New Hospitals Programme use Healthwatch's definition for seldom-heard and underrepresented people, meaning 'those who use or might potentially use health and social services, and who are less likely to be heard by service professionals and decision-makers' (Healthwatch, 2021, p. 2). The New Hospitals Programme also refer to 'inclusion groups' when they refer to groups of underrepresented people to engage with. The New Hospitals Programme also highlighted a need to create meaningful engagement with the following groups:

• Ethnic minority groups,

• Carers,

• People with disabilities,

• Lesbian, Gay, Bisexual, Transgender, and Queer people,

• People who are homeless,

• Younger people,

• People with language barriers (Sign language users and the d/Deaf community),

• Digitally challenged,

• Gypsy, Roma Traveller (transitory communities),

• Military veterans,

• Senior citizens,

• Pregnancy and maternity,

• Substance misuse,

• Ex-offenders,

• Mental health challenges,

• Rural/farming communities,

• Low income/unemployed,

• Single parents.

The term engagement is used interchangeably with 'involvement', 'participation', 'consultation' and 'patient and public voice' (NHS England, 2017). NHS England (2017) defines engagement as 'enabling people to voice their views, needs and wishes, and to contribute to plans, proposals and decisions about services'(NHS England, 2017, p.9). The National Centre for Public Engagement defines engagement as 'a two-way process, involving interaction and listening, with the goal of generating mutual benefit' (NCCPE, 2022). 'Engagement mechanisms' are processes, techniques and instruments for enabling the involvement of the public, patients, and communities (Rowe and Frewer, 2005).

Lancashire and South Cumbria New Hospitals Programme's Approach to Engagement

The New Hospitals Programme has developed a Communications and Engagement Strategy with input from the Communications and Engagement Oversight Group, the Consultation Institute, the Department of Health and Social Care (DHSC), NHS England and NHS Improvement. Within the strategy, the goals, objectives and principles of the programme's engagement and communication are outlined as follows:

The goals for communication and engagement:

To make sure people are:

1. Aware and informed about the proposals,

2. Trusting and supportive of the decision-making process - know how to be involved,

3. Aware of why decisions have been made,

4. Enthused about what is possible.

The objectives for communication and engagement:

1. Ensure key audiences are aware and informed about the New Hospitals Programme and future proposals,

2. Engage key audiences so that they trust and support the New Hospitals Programme process and understand how they can get involved and share their views,

5. Educate key audiences about the rationale for proposals and decisions,

6. Enthuse audiences about what is possible,

7. Create a sustainable communications and engagement legacy,

8. Ensure best practice in terms of inclusivity, accessibility and reach of communications and engagement activity.

The principles were:

Transparency
Clear and consistent record keeping and a strong governance process, with discussions and engagement events recorded, and records of materials and actions agreed, retained, and catalogued.

Inclusivity
Ensuring that the Programme's overall design considers and prioritises all potential audiences, and that seldom listened to communities and minority groups are included and feel understood and represented.

Being open-minded (No pre-determined outcome)
No decisions will be made ahead of a public consultation. The Programme will ensure that the communications and engagement messaging and approach makes this clear, and invites the views of the public, staff, and stakeholders to help inform and shape proposals.

Flexibility
The engagement process itself should be as long as is reasonably required and proportionate to the change being considered. It should include adequate time for all responses to be carefully and conscientiously considered, and for the Lancashire and South Cumbria New Hospitals Programme to be agile and responsive to feedback as needed.

Meaningful
The communications and engagement programme will aim to provide meaningful input into the business case and generate information and a process that will help participants to give an informed opinion on the issues being consulted on.

Clarity
The communications and engagement programme will use Plain English and jargon-free language to ensure maximum clarity and understanding amongst our audiences.

To engage underrepresented people, the LSCNHP aimed for the following:

• Proactively reach out to people with protected characteristics under the Equalities Act (2010). This includes age, disability, gender reassignment, marriage and civil partnerships, pregnancy and maternity, race, religion or belief, and sex or sexual orientation.

• Concentrate on engagement with those who will be most affected by the changes, including 'patients who use the hospitals regularly, especially those with mobility, stamina, dexterity and mental cognisance, those who experience health inequality and those who need hospital services at time of needs, maternity and A&E' (LSCNHP Communication and Engagement Strategy, 2022, p.5).

- Reach the digitally excluded, which would include older people, people without a job and people with disabilities.

- To have accessibility and inclusivity at the heart of the strategy. Aiming to reach and engage people of all ages, communities, and health requirements with 'the widest variety of communications and engagement touchpoints' (NHP Communication and Engagement Strategy, 2022, p.5).

- Recognise the ways that groups choose to participate.

- Ask meaningful questions in accessible ways.

- Use 'creative approaches to create exception communications materials with energy and vibrancy' (LSCNHP Communication and Engagement Strategy, 2022, p.5).

Statutory Duties

The NHS and New Hospitals Programme have a statutory duty to ensure that patients and potential patients are involved in the development and consideration of proposals for changes to services that would impact the services provided to them or the range of health services available to them.

The right to be informed is enshrined in the NHS Constitution for England:

'The public: has the right to be involved directly or through representatives, in... planning of healthcare services commissioned by NHS bodies,... development and consideration of proposals for changes in the way those services are provided, and in decisions to be made affecting... operation of those services' (HM Government, 2021).

In relation to the categories of protected characteristics it sets out, the 'public sector equality duty' (Section 149 of the Equality Act 2010) requires Clinical Commissioning Groups in the exercise of their functions, to have due regard to the need to:

- Eliminate discrimination, harassment, victimization, and other prohibited conduct,

- Advance equality of opportunity, and

- Foster good relations.

Mapping Current Engagement Practice

The Lancaster University team reviewed the New Hospitals Programme's engagement mechanisms with a focus on mechanisms used with underrepresented people. This review was supported by ongoing conversations with the New Hospitals Programme communications and engagement team, conversations with stakeholders, such as Healthwatch and documents reporting on the engagement activity written by the New Hospitals Programme team. The engagement mechanisms were mapped, including details of who engaged, how the engagement was implemented and additional information regarding underrepresented groups' participation and accessibility to resources and events.

Notes from the conversation with Healthwatch are included in Appendix 1 and notes from the conversation with a communications and engagement consultancy involved in conducting interviews with underrepresented people are included in Appendix 2.

Engagement Mechanisms

Table 1 shows the New Hospitals Programme engagement mechanisms and their target audiences. Two of the engagement mechanisms, *Healthwatch Together Focus Groups* and *Service User Representative Interviews* focused specifically on engaging underrepresented people.

Table 1: LSCNHP Engagement Mechanisms and Target Audience

Engagement Mechanism	Target Audience
Online surveys	Public
Market Research Interviews	Public
Healthwatch Together Roadshow Events	Public
The Big Chat	Staff; Foundation Trust members; voluntary, community, faith and social enterprise sector (VCFSE) reps; patient reps
Healthwatch Together Focus Groups	Underrepresented people/inclusion groups, VCFSE representatives
Social media platforms	Public
Colleague Summits	Staff
LSCNHP programme team-led briefings/drop-in sessions	Staff
Service user representative interviews	Organisations representing service users/patients
Patient Engagement	Service users/patients

Engagement Mechanisms used with Underrepresented People

Further details on the engagement mechanisms used with underrepresented people are included in this section. Further details on the other engagement mechanisms are included in Appendix 3.

Healthwatch Together Focus Groups – Phase 1

The focus groups were conducted by Healthwatch Together. Healthwatch Together includes four Healthwatch organisations; Blackburn with Darwen, Blackpool, Cumbria and Lancashire. The four organisations have a collaborative partnership to deliver engagement across the Lancashire and South Cumbria Integrated Health and Care Partnership. 142 participants from 20 different inclusion groups participated in the focus groups. These participants were recruited through the Healthwatch website and social media.

The focus groups were described by the New Hospitals Programme as an opportunity for underrepresented groups to share their thoughts, hopes, fears and thoughts on the clinical benefits of new hospital facilities. They were also described as a way to generate and maintain interest through a strong community presence, as well as an opportunity to 'educate' community groups and provide feedback.

The first phase mainly took place online with some face-to-face engagement in Blackpool (due to Covid-19 restrictions). This was followed by some one-to-one conversations. A hybrid methodology of face-to-face and virtual online workshops was used to mitigate the risk of digital exclusion and Covid-19 concerns. This was determined by the individual preference and risk Covid-19 mitigation strategies in place among the specific groups.

The New Hospitals Programme stated that the engagement approach was tailored to the communication needs of the specific groups in consultation with Healthwatch. Easy Read materials were requested and provided in print and online. Biographies of Healthwatch staff were sent to participants beforehand to reduce social anxiety. Participants were able to provide feedback in the chat function, thus giving people more time to consider and respond to what was being said.

Healthwatch Together Focus Groups - Phase 2

Healthwatch Together recommended a series of targeted focus groups for underrepresented audiences, who were not successfully reached in the first round of engagement activity. The gaps identified were:

• Sign language users and those who were d/Deaf,

• Older adults and people with multiple or long-term conditions,

• People with physical disabilities,

- Unemployed or people on low incomes, single parents,

- Prison populations,

- People from rural communities,

- People with mental health difficulties and people who misuse substances.

In the second phase, thoughts were shared on a longlist of proposals with 93 participants in 9 focus groups with communities who had not previously engaged. The focus groups took place online and offline to avoid digital exclusion and reduce Covid-19 risks. Participants were asked to select their most and least preferred proposal and provide their reasons. Healthwatch co-hosted and attended community group meetings, providing context on the longlist. In-depth case studies were created through some individuals through one-to-one conversations.

The underrepresented groups voiced their negative experiences of the existing hospitals, which included difficulties with accessibility. As a result, many did not trust that a new site would improve their experience of accessing hospitals. Healthwatch Together believes that there is a need to provide ongoing communication to the groups that explain how their contributions made a difference to the New Hospitals Progamme. However, both Healthwatch Together and the New Hospitals Programme feel that providing feedback effectively is a significant challenge in the engagement process.

Interviews with Underrepresented Community Group Representatives

Interviews with 13 community group representatives conducted by a communications and engagement consultancy. The New Hospitals Programme provided a list of people who they wished to engage with further.

- Refugees/asylum seekers,

- Military veterans,

- Those on low incomes/socially deprived,

- People who are blind or visually impaired,

- People who are deaf or hearing impaired,

- Those with mental health difficulties or cognitive conditions,

- People with communication difficulties,

- People with education/training difficulties,

- People with physical disabilities,

- People with all disabilities.

The groups were identified through desk research and Healthwatch contacts. A set of questions were sent to the groups before the interview took place. The interviews used pre-agreed questions regarding proposals for hospital facilities, one-to-one conversations with community group representatives and some group calls focused on certain conditions or communities.

To make the interviews more accessible, the survey was sent to representatives involved in community groups. The aim was to make it easier for digitally disengaged people to take part. Onboarding support was provided for online groups to increase the confidence of participants.

The Evidence Base

A total of 50 documents outlining best practices for engagement with underrepresented people and communities were reviewed, drawing out information that corresponded with the categories used for mapping the LSCNHP's current engagement practice. Through the evidence review, the team aimed to discover best principles, values, best practice and existing frameworks for engagement that would be useful to the New Hospitals Programme's engagement with underrepresented people and which would also reveal gaps in research to inform further work. Evidence was reviewed from 2007 to 2022. We used 2007 as the starting point because it was at this time that the new Health and Social Care Act (2008) laid down the responsibility to include patients and the public in the planning and delivery of care.

The literature and documents reviewed from the evidence base included the following:

- Literature reviews covering engagement, involvement and participation of underrepresented/seldom heard people in research and projects aiming to influence and shape services, provision and policy. This included examples from health services, public services, social care and policymaking.

- Reports from local, regional and national authorities and organisations, including UK and international organisations with expertise engaging in underrepresented/seldom-heard people.

- Toolkits and best-practice guidance from organisations and charities specialising in engaging with underrepresented/seldom-heard people.

The New Hospitals Programme highlighted groups of underrepresented people with whom they wished to engage further. Therefore, some of the literature review was targeted at engagement, participation and involvement of these groups, which included d/Deaf communities, people with disabilities and ethnic minority groups.

The Lancaster University team conducted a thematic analysis of the literature, which drew out some important and reoccurring themes from the review of the evidence base. Throughout this process, the New Hospitals Programme team and a stakeholder group (explained in the next section) were involved in discussing the key themes and how they would be relevant to the New Hospitals Programme engagement practice.

Information from the evidence base was organised under the following headings:

• Details of how the mechanism was implemented, including key features and components.

• Who engaged with the mechanism.

• Details on how the engagement mechanism was tailored for people with different characteristics.

• Details of underpinning principles and/or values.

• Details of guidance and toolkits reported.

• Whether the activity was intended to be a discrete (e.g. one-off event) intervention, or more continuous (e.g. community participation initiative).

• Level of the individual, group and/or community.

• The consequences and/or impact of the activity.

Stakeholder Engagement Group

The project engaged with the existing New Hospitals Programme Communications and Engagement Oversight Group (CEOG). CEOG is made up of representatives from a range of local NHS organisations, including all the local NHS Trusts, Central Lancashire and Morecambe Bay CCGs, lay members and the integrated care system, along with regional NHSE/I communications representation and with input from the Consultation Institute. Throughout the project, the group were updated on the project's progress and invited to actively participate. The stakeholder group fed into the engagement themes and aspirations for the New Hospitals Programme's engagement with underrepresented people.

Spectrum for Public Engagement

In public participation practice and literature, numerous models of participation have been produced that seek to assist with selecting and understanding the level of participation that the public have in participation processes. The first and most cited model is Sherry Arnstein's Ladder of Citizen Participation (Arnstein, 1969), which has been critiqued for its simplicity and for implying that the higher rungs on the ladder are superior forms of engagement (Tritter and McCallum, 2006). The IAP2 Spectrum for Public Participation (2018) is a frequently and internationally used spectrum for deciding how members of the public will be involved in the participation process (Represented in Figure 1).

The IAP2 Spectrum was presented to and discussed with the New Hospitals Programme team and stakeholder group. The groups indicated that the current engagement activities were concentrated in the 'inform', 'consult' and 'involve' sections (indicated in figure 1 in yellow), however, they would like to move into the collaborate section in the future. The bottom row labelled 'LSCNHP Mechanism' indicates where the LSCNHP team placed each of their existing engagement mechanisms.

The LSCNHP team felt that the heading on the second column 'consult' could be confused with the formal consultation requirements of the NHS and would be better renamed as 'engage'. The spectrum was reconfigured by the LSCNHP to become a wheel in which the LSCNHP could move between the modes of engagement (see page 22).

The IAP2 Spectrum for Public Engagement Mapped Against LSCNHP Engagement

	Inform	Consult	Involve	Collaborate	Empower
Public Participation Goal	To inform the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/ or solutions.	To obtain public feedback on analysis, alternatives and/ or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision, including the development of alternatives and the identification of the preferred solution.	To place final decision making in the hands of the public.
Promise to the Public	The organisation will keep the public informed.	The organisation will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision(s).	The organisation will work with the public to ensure that their concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	The organisation will look to the public for advice and innovation informulating solutions. The advice and recommendations will be included into the decisions to the maximum extent possible.	The organisation will implement what the public decide.
LSCNHP Mechanisms	Blog and website updates.	Big Chat, Healthwatch Together Roadshow and electronic survey.	Focus groups and Big Chat.	No existing examples from the LSCNHP.	No existing examples from the LSCNHP. It was acknowledged that this stage is problematic due to limitations on the building new hospitals.

**Increasing impact on the decision** →

Online Engagement with the Stakeholder Group

In May 2022, the Lancaster University team, the New Hospitals Programme team and the stakeholder group had an online discussion via Microsoft Teams where the emerging themes from the evidence base and the engagement spectrum were presented and discussed. The discussion was organised onto an interactive Google Jam Board during the discussion to capture the response (see figure 2 below). In this conversation, some of the following points were raised:

• Changing the engagement cycle into a wheel to allow moving in between the engagement types.

• The use of LSCNHP Ambassadors to reach underrepresented people.

• Engaging with local government as part of a place-based agenda.

• A need to explore ways in which the LSCNHP and the national NHP can maintain trust.

Figure 2: Google Jamboard from the Online Engagement with the Stakeholder Group
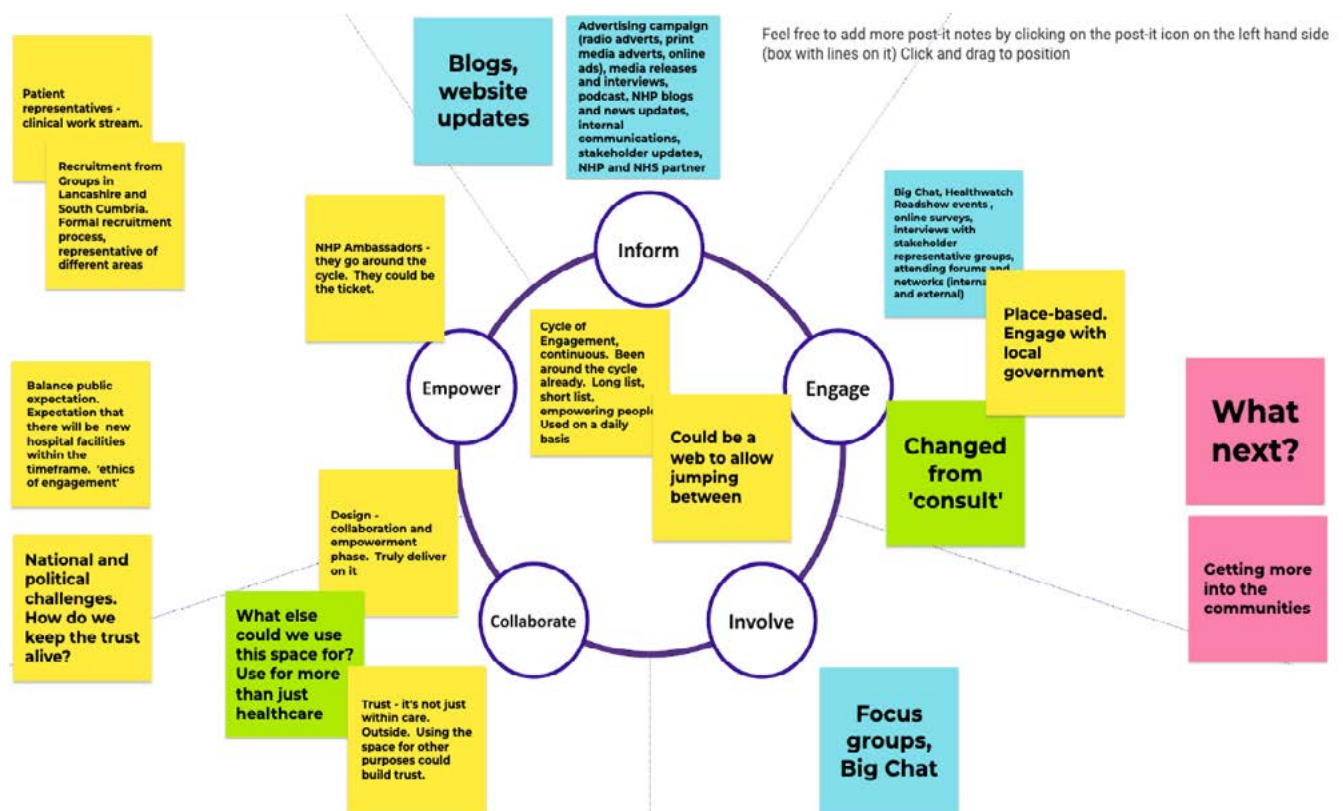
The New Hospitals Programme Wheel for Engagement

The New Hospitals Programme team, stakeholder group and Lancaster University team co-designed a wheel for informing engagement with underrepresented people based on the IAP2 Spectrum for Public Engagement. The LSCNHP Wheel for Informing Engagement allows teams to move between the different stages of engagement and introduces an 'engage' stage instead of IAP2's 'consult'.

Figure 4: The LSCNHP Wheel for Engagement
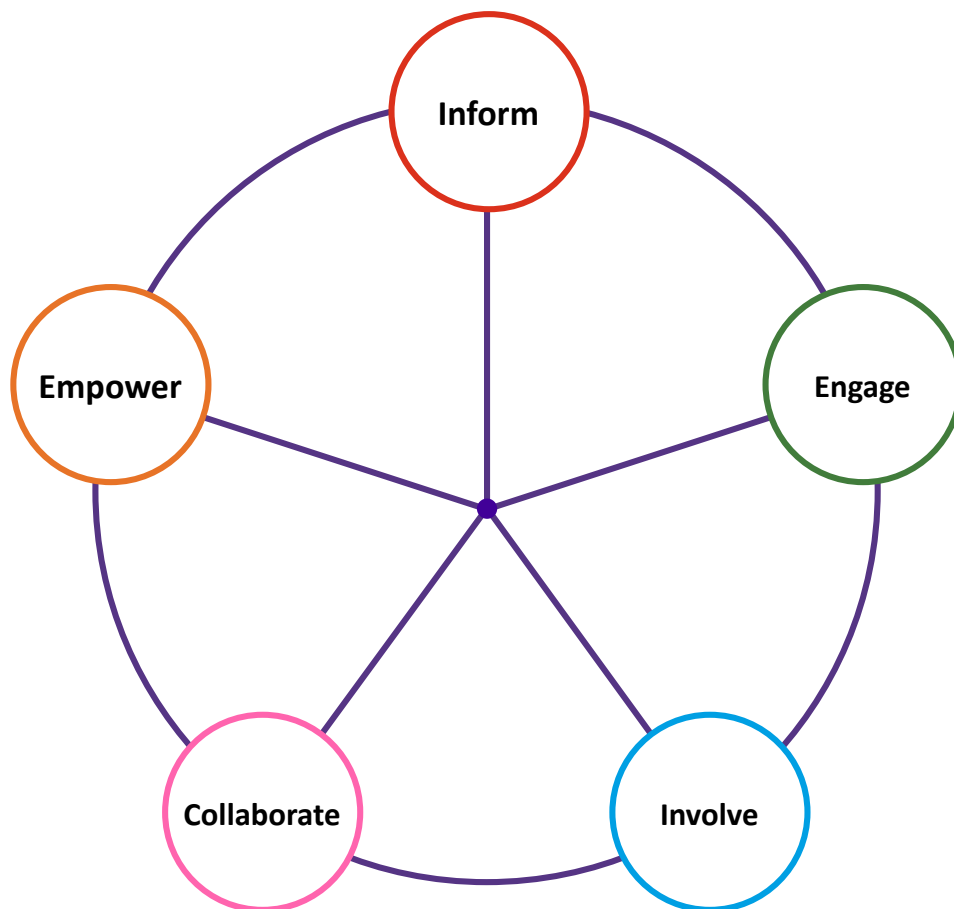
Inform - To inform the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.

Engage - To obtain public feedback on alternatives and/or decisions.

Involve - To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.

Collaborate - To partner with the public in each aspect of the decision, including the development of alternatives and the identification of the preferred solution.

Empower - To place final decision-making in the hands of the public.

In-Person Workshop

In July 2022, the Lancaster University and New Hospitals Programme team met together at the Health Innovation One Campus at Lancaster University for an interactive workshop. During the workshop, the New Hospitals Programme team reviewed the themes from the evidence base and the mapping of their engagement practice. Following this, they voted on which themes to prioritise to discuss in the workshop. Each prioritised theme was discussed within the group to generate ideas and actions for the programme going forwards. The ideas and actions have been added to the mapping section. Following the workshop, the New Hospitals Programme team continued to review the remaining themes and add actions and ideas online. Plans to create an online toolkit were also discussed by the team.

The themes and the mapping of engagement with underrepresented people, which were reviewed by the LSCNHP team are included in the next section of this report. Comments from the LSCNHP team have been incorporated and reflections and actions from the team are highlighted in the text.

Figure 4: Discussing the themes and mapping exercise

Online Toolkit

The following ideas for a potential online toolkit were discussed at the workshop in July 2022.

Implementation

- A toolkit could be of use to NHS Lancashire and South Cumbria Integrated Care Board (ICB), Lancashire and South Cumbria Health and Care Partnership and the national New Hospital Programme.

- There would be a need to consider audiences for the toolkit. For example, novices or people with experience.

- The toolkit could be aimed at service managers and commissioners both inside and outside the NHS. As well as government and local communities.

- There would need to be a consideration for who would be responsible for the toolkit.

- The toolkit could be a live document, growing with experience.

- Feedback could be sought on the content of the toolkit.

- The toolkit could enable people to 'dip in and out'.

The toolkit could include:

- People from underrepresented groups and community groups could talk about the ideas within the toolkit.

- The cycle of engagement that was created through this project.

- A flowchart to select activities and mechanisms.

- Films explaining ways to engage with underrepresented people, which could be explained in their own words.

- The themes from the evidence base for discussion with different groups.

Themes and Mapping of Current Practice

Overarching Theme: Values and Principles

Values and principles are a foundation for engaging with communities and underrepresented groups. Values underpin the organisation's approach to meaningful engagement with underrepresented people. Values are deeply held beliefs that guide actions and behaviours (Nanschild, 2008). The values may inform a set of principles, which the organisation also uses as guidance. Shared values and principles are the start of meaningful and inclusive involvement of underrepresented people (Win Win Alliance, 2021). Equitable power, trust, mutual respect and cultural sensitivity are examples of principles that are frequently emphasised in the evidence base.

Key values for engaging with underrepresented people identified in the evidence base

- From a review of 55 articles, Harrison (2018) produced a list of the most common principles for engagement. The most common was respect for stakeholders, the second was equitable power, the third was trust, the fourth was transparency and openness and the fifth was diversity.

- Move away from participants 'having a say' to 'making a difference' (Kelleher et. al, 2014).

- NHS England is committed to ensuring that patient, carer and public voices are at the centre of shaping healthcare services and service development (NHS England, 2016a).

- Cultural sensitivity and competence are important (EMAHSN, no date; Latif, 2010; Farooqi et al., 2018). Cultural competency is explained by Farooqui et al. (2018), meaning to value diversity and promote inclusivity. It involves having self-awareness, cultural knowledge, and skills to foster culturally effective and ethical communications, interactions and relationships with people of various cultural backgrounds (Cronin and Ward, 2004, as cited in Farooqui, 2018). It involves 'cultural humility', a lifelong commitment to self-evaluation and recognition that one's own culture is not the best or only one (Schuessler, et al., 2012, as cited in Farooqui, 2018).

- Mutual respect is highlighted as critical (Holroyd-Leduc et al., 2016; Meakin et al., 2017). For example, through listening to each other and valuing each other's knowledge.

- Valuing lived experience by viewing people as experts in their own experience (Holroyd-Leduc et al., 2016; Meakin et al., 2017) is also important.

- Addressing power imbalances (Holroyd-Leduc et al., 2016; Harrison et al., 2019) is key. This could include including users in each part of the engagement process, including defining the purpose of the activity, objectives, outcomes, setting the timeframe and evaluation. It is important to genuinely listen, avoid jargon, meet access needs, share relevant information and not leave service users' ideas until last on the agenda (Meakin et al., 2017).

- Meaningful engagement goes beyond 'passive consultation' (Holroyd-Leduc et al., 2016).

- Co-production as a process enables meaningful engagement with underrepresented groups (Kenny et al., 2015; Local Government Associate, 2019).

- Engagement is about a two-way relationship (Local Government Associate, 2019).

- Examples of values and best practices for engagement have been published by the New Zealand Government in their [Principles and Values for Community Engagement](#).

Values and Principles for the LSCNHP	
Current Practice	**Reflections and Questions for Current Practice**
The LSCNHP has a set of aims, which are to ensure that its audience were: • Aware and informed about the proposals. • Trusting and supportive of the decision-making process and knowing how to be involved. • Aware of why decisions have been made. • Enthused about what is possible. **The principles were:** • Transparency, • Inclusivity, • Being open-minded, • Flexibility, • Meaningful, • Clarity.	• The emphasis of the existing aims views patients and the public as an audience to be informed and educated, rather than involved in the process and offer their lived experience. In this context, the power may remain more with the LSCNHP, rather than the public and patients. • The aims perhaps could be viewed as weighted more towards communication over engagement.

Opportunities for the LSCNHP

- Could the LSCNHP develop values and principles specifically for underrepresented groups? This could also include values and principles for involving communities in the development of hospitals and services.

- Could developing the principles involve underrepresented people?

Ideas, Actions and Reflections from the LSCNHP

- Flexibility was challenged by Covid-19. Future engagement could be more flexible.

- Review LSCNHP communications and engagement strategy objectives and principles considering research findings.

Trust

Building and maintaining trust between underrepresented people, engagement practitioners and organisations is critical. Many people do not have trust in authorities and the public sector (Farooqi et al., 2018; Unwin, Meakin and Jones, 2020; NIHR, 2021). Some people fear reprisal if they say anything negative (Beresford, 2013; NHS England, 2017) and they need reassurance that this is not the case. Considerable time is needed to build trust with people (Farooqi et al., 2018; Urban Institute, 2021).

Suggestions for Building Trust

- A shift away from process-driven consultation models to fostering an 'ethos of strategic, continuous and meaningful engagement' (Local Government Associate, 2019).

- Clearly explaining how the project and engagement will benefit the community (Farooqi et al., 2018).

- Being open, honest, and transparent. Explaining the benefits of decisions and any limitations (NHS England, 2017).

- Acknowledge power dynamics (NIHR, 2021).

- Being mindful of 'elitist structures of participation' (Kelleher, Seymour and Halpenny, 2014), which may be standard in professional contexts, but unsuitable for engaging underrepresented people. Ensure that engagement is accessible (Holroyd-Leduc et al., 2016).

- Showing people that they are valued by recognising and rewarding contributions and giving feedback on their involvement (NHS England, 2017).

- Building mutual respect can tackle trust issues (Changing Lives and Centre for Public Impact, 2020; Unwin, Meakin and Jones, 2020).

- Some people feel 'researched out' and therefore engagement takes persistent networking and attendance at conferences and events (Unwin et al., 2020).

- Poor engagement can result in tokenism (Harrison, 2018).

Trust for the LSCNHP

Current Practice	Reflections and Questions for Current Practice
• A partnership with Healthwatch Together, which has already built relationships with some community groups over time. • Healthwatch felt that more time was needed than they were given to build relationships and set up workshops. • Regular updates on the progress of the programme on the LSCNHP website, LSCNHP Facebook page and LSCNHP Twitter account. Also media releases for milestone updates and advertising campaign. • The Healthwatch *Workshops with Seldom Heard People Report 2* includes quotes from people interviewed. Some comments suggest there is an existing lack of trust in the NHS due to past experiences. • *"It would take hours to be seen if they were taking in loads more patients. Yeah they'd have more staff but that never works."* (Homeless person). • *"I can't get any help and every time I've tried, I'm told I need an address. Even when I've been with my boyfriend in A&E I have been asked to leave by staff because they say I'm homeless and they don't want me in there."* (Homeless person). • During engagement, underrepresented people discussed topics relating directly to the building of new facilities. Underrepresented people also highlighted the importance of big-picture themes, such as holistic care, collaboration, prevention and tackling health inequalities.	• The previous negative experiences with service delivery in hospitals impact underrepresented peoples' willingness to engage in the LSCNHP. • Underrepresented people may also feel that negative feedback may impact their healthcare. • This theme links with other themes including accessibility, feedback, level of engagement and sustainability. • How has LSCNHP maintained the relationship and trust? • Would it be possible to spend more time building trust with underrepresented people throughout the LSCNHP process? • How might the LSCNHP acknowledge power dynamics between them and underrepresented people? • Are some of the engagement processes standard in professional contexts but could be seen as elitist to underrepresented groups? • How can mutual trust and respect be built between the LSCNHP and underrepresented groups? Some starting points are included in the other themes.

Comments on Trust Issues from Underrepresented Groups

There were a number of comments from underrepresented people regarding trust in future changes to hospitals. For example:

- *"It would take hours to be seen if they were taking in loads more patients. Yeah they'd have more staff but that never works." (Homeless person).*

- *"I can't get any help and every time I've tried, I'm told I need an address. Even when I've been with my boyfriend in A&E I have been asked to leave by staff because they say I'm homeless and they don't want me in there." (Homeless person).*

- *"It is really difficult for the deaf, there is no help and you have to wait all day until there is someone who can understand you." (Person from d/Deaf community).*

- *"The deaf community is just a small part of the hearing world; we are fighting and we are just not heard." (d/Deaf community).*

- *"The government know nothing about the deaf, interpreters need to be booked and know how long it takes. Sometimes it takes 3-4 days to arrange. It is a big problem and the deaf have nothing, we are fighting and we give up, we are exhausted. Who do we talk to? We don't know who to ask." (d/Deaf community).*

- *"It is more that training of staff which needs to be improved than a new site in my opinion." (Person accessing mental health support services).*

- *"We should be seen as experts in ourselves, we know what it right for us and we need to be taken seriously." (Person accessing mental health support services).*

Opportunities for Building Trust on the LSCNHP

- Understand and build in ways to build trust and reassurance into the engagement process.

- Create opportunities for strategic, continuous and meaningful engagement and feedback with underrepresented people.

- Could updates on the programme's progress be made less formal and inclusive to underrepresented people?

- How are updates shared with those who do not follow the LSCNHP on social media, specifically underrepresented groups?

- Demonstrating that people are valued by the LSCNHP through rewarding contributions and providing feedback on their involvement.

Ideas, Actions and Reflections from the LSCNHP

• Flexibility was challenged by Covid-19. Future engagement could be more flexible.

• Review LSCNHP communications and engagement strategy objectives and principles considering research findings.

• Banking questions (FAQs).

• Not in control of timeframes. Can we come back?

• Restrictions of timeframes. Can the timeframes be better explained to groups?

• Take time to have a coffee with people.

• Therapists and nurses are good at building trust when interacting with groups.

• Aim to be open and be an open link to the New Hospitals Programme.

• Link with community leaders who already have built trust and work directly with community members.

• Show the evidence of listening. e.g. being able to show that feedback sharing concerns regarding having a single hospital in a central location have been considered in the decision-making process.

• Explore delivering 'you said, we did' in a range of different formats.

• Interview (and make films of) people and groups discussing the action on the feedback/ideas they gave.

• Being open about what you can or can't talk about.

• Answers questions when you can.

• Build relationships beyond the project.

Diversity and Inclusion

Diversity refers to 'respecting and valuing all forms of difference in individuals' (INVOLVE, 2012, p. 2). Inclusion refers to 'positivity striving to meet the needs of different people and taking deliberate action to create environments where everyone feels respected and able to achieve their full potential' (INVOLVE, 2012, p. 2). Patients, carers and the public should have equal opportunities to be involved (NHS England, 2016). It is impossible to create a full list of people who are underrepresented and assigning labels is problematic, as it suggests everyone within a group is the same (INVOLVE, 2012). The diversity of people with shared characteristics must be understood at the beginning of the engagement process (Young and Hunt, 2011; Parnez and Martowicz, 2015; Ekezie et al., 2021). For example, there are differences in culture, language, genetics, service user and health status, as well as differences across age groups and migration status (Ekezie et al., 2021). It is argued that a range of different perspectives is more important than numerical representativeness in decision-making processes (Kelleher, Seymour and Halpenny, 2014; Local Government Associate, 2019).

Suggestions for ensuring diversity and inclusion

- Count representation, not numbers (Kelleher, Seymour and Halpenny, 2014).

- Avoid including only those who are available, and have the capacity to participate and self-elect, as it limits others with diverse perspectives (Kenny et al., 2015).

- Recruit people who are from excluded groups participate to introduce diverse views to stakeholder groups (Latif, 2010).

- Consider engaging populations who are overlooked due to their geographical proximity (Kenny et al., 2015).

- Actively look to engage those who know the least about proposed changes and plans (Local Government Associate, 2019).

- Be aware that community leaders may introduce bias and assume they know more than the group they represent and that not everyone interacts with community groups (Farooqi et al., 2018).

- Avoid assumptions about an individual's capacity to participate. Assume competence to participate (Holroyd-Leduc et al., 2016).

Suggestions for engaging specifically with people with disabilities

- United Nations Convention on the Rights of Persons with Disabilities (2006) is an international agreeement about protecting and promoting the human rights of disabled people throughout the world. It states that disabled people's 'full and effective participation and inclusion' should be supported (Equality and Human Rights Commission, 2006).

- Having a social model of disability is viewing the barriers faced by disabled people as barriers created by society, not because of their health impairments and conditions (Ministry of Health, 2016; Meakin et al., 2017).

- Ensure that access to information and services, social attitudes and behaviours, and the built environment are not causing barriers to equal participation for disabled people (Ministry of Health, 2016).

- Many disabled people do not trust the public sector, therefore there needs to be an investment in trust building (see the Trust theme)(Urban Institute, 2021).

- Do not assume that written communication is not a barrier for the d/Deaf community (Young & Hunt, 2011).

- Always ask what words someone prefers to use. Disabled people are hindered by attitudinal and environmental barriers. Some people do not refer to themselves as having a disability and may instead identify as being part of a community, for example, the Deaf community. Terms like 'hearing impaired' may also be viewed negatively (Ministry of Health, 2016).

- A person who identifies as deaf written with a lowercase d indicates they have a severe hearing problem. A person who identifies as Deaf with an uppercase is indicating they are culturally Deaf and identify they are part of the Deaf community. People in the Deaf community often communicate in sign language as their first language. d/Deaf refers to both groups. (Young & Hunt, 2011, SignHealth, no date).

- Communicate directly with the person who you are trying to engage, rather than an interpreter or assistant (Ministry of Health, 2016). This includes considering the physical surroundings, including the layout of the room, and maintaining eye contact.

- The New Zealand Government Ministry of Health (2016) has a comprehensive guide to engaging with people with disabilities.

Suggestions for engaging with ethnic minority groups

- Written materials may not be the most appropriate way of communicating, creating barriers to understanding (Farooqi et al., 2018).

- Some languages are better spoken than translated into written materials (Latif, 2010).

- Details matter; dress appropriately and order food that is appropriate (EMAHSN, no date).

- Consider issues of heterogeneity, for example, differences between religions and different regions (Farooqi et al., 2018).

- Beware of tokenism and that mixing ethnic minority groups can cause tension. Consider gender, age, religion and cultural background (Farooqi et al., 2018).

- A useful guide is *Effective Methods for Engaging Black and Ethnic Minority Communities within Healthcare Settings* by Latif (2010).

Suggestions for engaging with young people

- Article 12 of the UN Convention on the Rights of the Child states that children and young people have the right to have and express an opinion in all matters and judicial and administrative procedures that affect them.

- Consider engaging different age groups. For example, 20% of the population is under twenty years old in England and 14% have a long-term illness.

- Do not leave young people out (NHS England, 2016b) and consider recruiting youth ambassadors (Kelleher, Seymour and Halpenny, 2014; NHS England, 2016b).

- Kelleher, Seymour and Halpenny (2014) have a list of questions to ask when looking to meaningfully engage young people. Larsson et al. (2018) offer guidelines and frameworks.

Diversity and Inclusion for the New Hospitals Programme

Current Practice	Reflections and Questions for Practice
• The term 'inclusion' is used to refer to 'underrepresented people who use (or might use) health or social care services, but who are less likely to have voice heard by decision makers or service professionals' (Section 5.3 of Engagement Insight Synthesis Report). • Delivery of a set of workshops with a range of community groups and services for underrepresented people. • Interviews with additional community group representatives to address gaps in engagement with underrepresented groups. • Healthwatch Roadshows, which engaged with citizens in public spaces and may engage underrepresented people. As they are mobile, they had the potential to engage people who are not members of community groups, at different times of the day and in locations where they already visit. • 8,370 underrepresented people have participated (27% of the total) according to the *Your Hospitals, Your Say* report published in September 2022. This can be broken down as 912 from ethnic minority groups, 1,212 people with disabilities, 183 LGBTQ+ people, 851 carers, 3609 senior citizens, 63 younger people, 129 users of pregnancy and maternity services, 154 sign language users, 208 military veterans and 12 people who are refugees and asylum seekers.	• It is highlighted in the evidence base that within 'inclusion groups' there are significant differences between the characteristics, needs and preferences of underrepresented people. • Assuming a community group representative can represent the needs of a whole group sufficiently is problematic according to the evidence base. There is a risk that assumptions are made for people who do not have the capacity to be directly involved. There is also a risk that community group representatives can introduce bias and assume they know more than the group. • There is also a risk of assuming that all underrepresented people engage with community groups. • The number of people attending events or visiting a website does not represent the extent that someone was engaged. • How might engagement be captured beyond numerical representation? • Are young people outside of Blackpool sufficiently represented? • Is it possible to take a targeted approach to engage with those who have not been part of the engagement activities to date?

Opportunities for Diversity and Inclusion on the LSCNHP

- Recruit representatives for underrepresented people to LSCNHP stakeholder groups to include diverse viewpoints. Avoid only including readily available people and have the capacity to participate and self-elect.

- Consider engaging people who are excluded due to their geographical location.

- Aim to actively engage those who know the least about proposed changes and plans.

- There are gaps in existing knowledge of how to engage with d/Deaf community, which could be explored to create best-practice in this space.

Ideas, Actions and Reflections from the LSCNHP

- Links to traditional methods and voicing their opinions.

- Asking how people want to engage and sensitively.

- Anonymous feedback.

- Signed video/blogs.

- Speak to people in training about their future work environment. Nursing schools and medical schools.

- Bringing in people from the community.

- Young people – engage in little bits of the conversation.

- Flexibility/adaptation.

- 'We don't know, what we don't know' e.g. LSCNHP need to find ways to encourage people to speak up, especially if they are quiet or find it difficult to express themselves.

- Big Chat format – anonymous platforms for feeding in.

- Values and principles underpin the approach to inclusion and diversity.

- Getting involved on the doorstep. How to generate passion?

- Someone in the community delivering messages, for example, the under 20s.

- Speaking about accessibility can be uncomfortable.

- Asking people how they want to be included.

- Audio – make resources. Fatigue to read, videos and signing.

- Knowing accessibility of those engaging and inviting in to contribute etc.

- Sign language – learning how to flex and adapt (values and principles).

- Equalities impact assessment.

- Youth forums – limited engagement.

Level of Involvement

There is a need to consider the range of ways that people from underrepresented groups can be involved in the different stages of planning and delivering engagement and associated projects. Where possible involving people in every stage of the engagement process, from planning, recruitment, facilitation and sharing the outcomes (EMAHSN, no date; Beresford, 2013; Cyril et al., 2015; Flynn, Walton and Scott, 2019; Harrison et al., 2019; NIHR INVOLVE, 2019; Ekezie et al., 2021). Involving people at all levels of engagement can support recruitment, participation and retention, as well as create a sense of ownership (Bonevski et al., 2014). Be aware that community representatives may not be able to represent the views of the whole community (Kelleher, Seymour and Halpenny, 2014; NHS England, 2017; Singleton, Jones and Hanumantha, 2017).

Suggestions for influencing the participants' level of involvement

- Co-produce and co-design processes. This could involve working with people in equal partnership to design, develop and evaluate (NHS England, 2017). This can increase involvement, counter-act engagement fatigue and build trust.

- Consider advocacy if someone is not comfortable or motivated to participate. This can be more honest than participation that is not genuine (Kelleher, 2014).

- Consider using a Community Researcher Model: training community members to assist with the research and engagement.

- A challenge is equalising the power and expertise between the participant and the researcher (Flynn, Walton and Scott, 2019).

- Benefits delivered to participants from meaningful engagement can include; a sense of value and purpose, new knowledge and skills, and increased motivation, awareness and confidence (Flynn, Walton and Scott, 2019).

- A review of studies using community engagement approaches to address health inequalities faced by underrepresented groups (Cyril, 2015) revealed a link to engagement on the first two stages of the IAP2 Spectrum (discussed on page 19). Studies that achieved high levels of engagement (collaboration, partnership and empowerment) showed outcomes such as enhancing health promotion messages, improved health behaviours, overcoming cultural and access barriers and encouraging participation.

Level of Involvement for the LSCNHP

Current Practice	Reflections and Opportunities for Practice
The LSCNHP's approach to engagement has been informed by: • The Communications and Engagement Oversight Group, which contains representatives from the Lancashire and South Cumbria NHS Trusts, Clinical Commissioning Groups. • Communications and Engagement colleagues and lay members, and Lancashire and South Cumbria Health and Care Partnership. • The Consultation Institute (Not-for-profit best practice institute for public and stakeholder consultation in the public, private and voluntary sectors). • The Department of Health and Social Care (DHSC). • NHS England and NHS Improvement (NHSE/I). • Healthwatch Together (Healthwatch Blackburn with Darwen, Blackpool, Cumbria and Lancashire partnership). • Communications and engagement consultancy specialising in commercial strategy, communications, reputation management and board advisory services. • The LSCNHP team identify that their current approach to engagement sits within the inform, engage (previously labelled consult) and involves sections of the IAP2 Spectrum of Public Participation. These centre around informing the public, obtaining feedback and working to ensure the public's aspirations are understood and considered.	• Where and how could underrepresented people be actively involved in various stages of the engagement process? • Could underrepresented people and those who work closely with them in various community groups be part of the oversight group? • How might voluntary, community, faith and social enterprise sector help drive and inform engagement? • Creation of opportunities for underrepresented people to be more actively involved in the engagement process, including planning of engagement activities, delivery of engagement activities and sharing outcomes of the process. • Create opportunities for underrepresented people to have meaningful roles in the shaping of new hospitals and in engaging other represented people. • Consider exploring how meaningful co-production or co-design approaches can be built into the LSCNHP engagement strategy. • Exploration of a shift in 'collaboration' and 'empowerment' on the IAP2 Public Participation Spectrum. This could involve 'partnering' with the public in each part of the decision making and developing alterative solutions. • Explore co-production of workshop/focus group sessions with under-represented. groups.

Listening, Acting and Providing Feedback

A significant challenge for engaging with underrepresented groups is that many do not trust that organisations will genuinely listen and act on their ideas and views. It is therefore important that the organisation demonstrates how they have listened to ideas and what has happened as a result (Beresford, 2013; Ministry of Health, 2016; Meakin et al., 2017; Harrison et al., 2019; Healthwatch, 2021). The process of asking people to share experiences and taking action based on what they have said demonstrates that the organisation values people (Parnez and Martowicz, 2015; Meakin et al., 2017). Poor communication and engagement experiences can compromise any future public engagement (Ministry of Health, 2016). Feedback should occur early and appropriately, and clearly explain why ideas were unable to be implemented. It is recommended that time and budget should be allocated to the process of providing feedback (Meakin et al., 2017; Farooqi et al., 2018).

Suggestions for how to listen and act on what people say

- Demonstratable outcomes help address cynicism, disillusionment and consultation fatigue (Kelleher, Seymour and Halpenny, 2014).

- Kelleher, Seymour and Halpenny (2014) describe having demonstratable outcomes from the engagement as being meaningful engagement.

- Tailor the feedback for the community (Farooqi, 2018). For verbal or written feedback, the feedback needs to be engaging and relevant, providing information on the impact of contributions. The language needs to be jargon-free and consider that English is not everyone's first language (e.g. second generation ethnic minority communities).

- Farooqi (2018) provides guidance on verbal feedback, which can be delivered by revisiting the community. This should be announced early in the process. Delivering feedback through community leaders provides less control over message content and there may be problems if there are detailed queries. Focus groups similar to those used to gather input from people can be used to discuss the influence of the participants' contributions.

- Clearly translate information and avoid jargon (Farooqi, 2018; Healthwatch, 2021).

- Consider if engagement or communication should be written or delivered another way, for example visually (Farooqi, 2018).

- Be honest about anything that cannot or could not be delivered (Farooqi, 2018).

- Have realistic timescales to allow for outcomes to change if necessary (Meakin et al., 2017).

- Refer to the *Toolkit for Increasing Participation of Black Asian and Minority Ethnic (BAME) Groups in Health and Social Care Research* (Farooqi, 2018) for advice on feedback and other techniques.

Listening to, Acting on and Providing Feedback for the LSCNHP

Current Practice	Reflections and Opportunities for Practice
• Healthwatch and LSCNHP email community groups after engagement to say thank you for participating. • Updates on LSCNHP progress and decisions are shared on the website and social media. They are currently presented through text. • Details of the overall steps in the process are shared on the website on a timeline with images. • LSCNHP aim to communicate back to people about how their feedback has been used to influence the decision-making process. There are messages on social media every week, they will retweet LSCNHP partners, keep information up-to-date on the websites, produce a media release and collect people's emails to stay in touch.	• Providing feedback that shows how underrepresented people's views have been listened to and acted upon was highlighted as a particular challenge for LSCNHP and Healthwatch. • Currently, feedback mechanisms rely mainly on written communication, are presented formally and professionally, and contain jargon. This can be a barrier to engagement with underrepresented groups and trust building. • Is feedback the wrong term? Should the emphasis be on clearly demonstrating how the information shared in engagement activities was put to use? • Tailoring the feedback to the community. This could include asking people how they would like to hear back. • Exploring feedback beyond written communication, for example visually, in British Sign Language and verbally. • Exploring how to feedback clearly and appropriately, as well as explain why ideas cannot be implemented. • Allocating time and budget to feeding back. • This is an area which can help to build trust in underrepresented communities. Demonstrating that views are listened to and acted upon can make people feel valued. • The evidence base highlights the importance of demonstrating how feedback is used to avoid tokenism, however there are gaps in the detail on how to deliver the feedback. effectively.

Ideas, Actions and Reflections from the LSCNHP

• Allocating resources/budget to feeding back.

• Blogs – explaining what we've heard, why proposals developed from the shortlist, and how feedback inputs into decision-making. Case for change. Easy Read – developed with feedback via the LTHTR patient information group.

• Has the LSCNHP tailored the feedback to the different communities? Yes – have asked about preferences in a survey. Will be shaping reports in a variety of formats in Autumn.

• Is feedback is the wrong term?

• Programme follow-up.

• Thank you postcard – relationship building.

• Instagram.

• Healthwatch? Is there a better way of collaborating on this together as a wider health and care system?

• ICB and NHP.

• Communication versus engagement.

• Programme blogs. Who do they reach? Share them with Healthwatch. How do you get to the heart of the underrepresented groups?

• ICS/ICB Strategy and approach.

• Boundaries and national government changes.

• Should the programme get in touch with people who Healthwatch contacted? Trust?

• Patient experts – how do we get them to join us?

• Healthwatch – reach that LSCNHP does not have. Need support in execution – planning, motivation, not impartial.

• Your Hospitals, Your Say public-facing report in autumn.

Drawing on and Incorporating Local Knowledge

Drawing on and incorporating local knowledge and assets to ensure that when a new service or design is created for a specific location and reflects the context (Kilpatrick, 2009; Local Government Associate, 2019). This starts through engaging with local people, in a variety of locations, which vary from place to place, and not excluding those who are based outside the main towns and cities (Local Government Associate, 2019). Local communities may view government organisations as outsiders without little understanding of how the local community works (Kenny et al., 2015). Drawing on and incorporating local knowledge also involves creating links with local organisations and networks (Kilpatrick, 2009; Parnez and Martowicz, 2015; Unwin, Meakin and Jones, 2020; Healthwatch, 2021). Community organisations can help support and strengthen the planning and delivery of engagement activities with underrepresented groups and develop a mutual understanding (Kilpatrick, 2009; Kelleher et. al, 2014). Creating local partnerships can help understand local health beliefs and help to develop locally relevant health interventions (Kilpatrick, 2009). The engagement should seek to understand what is unique about health outcomes and accessing healthcare in specific geographical locations (Kilpatrick, 2009).

Suggestions for drawing on local knowledge

- Producing a map of local assets, including organisations, communities and knowledge (Local Government Association, 2019). Consider if there are already maps of local assets in the community that could be drawn upon.

- Engaging local communities should draw on community values and attitudes, take account of and draw on community resources (Kilpatrick, 2009).

- In some communities, including remote rural communities, people can be suspicious of change. Therefore, consider hiring people who live locally who can help to build and engage the capacity of the community (Kilpatrick, 2009).

- Consider the use of *Community Connectors* (Unwin, Meakin and Jones, 2020), *Community Champions* (Parnez and Martowicz, 2015) or *Community Researchers* (Healthwatch, 2021), which involves training community members to research and engage with underrepresented groups. This should involve local people with local knowledge, who can help across communities, explain the project, translate information and set up appropriate engagement times and venues (Unwin, Meakin and Jones, 2020).

- Look for networks and support beyond local organisations, particularly in smaller locations to ensure that people that often excluded are included (Ministry of Health, 2016).

- Take time to understand the customs, values, norms and community assets (including skills, social capital and organisations) (Kilpatrick, 2009).

- Kilpatrick (2009) includes best practice guidance for engaging with specific geographical communities.

Drawing on and Incorporating Local Knowledge for the LSCNHP

Current Practice	Reflections and Questions for Practice
• The LSCNHP acknowledges that 'the region of South Cumbria and Lancashire is large and complex, and including people living in cities with diverse cultures and communities, rural areas and coastal towns' (section 2.1 of Engagement Insight Synthesis). • The LSCNHP's 'ambition is to give people and communities equal access to the best possible hospital facilities, to help local people in the region live longer, healthier lives' (section 2.1 of Engagement Insight Synthesis). • Use of HARRI van to visit groups. The van visited Preston Market, Lancaster Sainsburys and a school in Kendal. • Healthwatch Roadshows visited supermarkets, markets, a bus station, a town centre, a college, a school car park, a housing estate (Kendal), and one Hindu community centre. Most participants who engaged with this were unaware of the LSCNHP, which indicates it was effective at expanding the reach of the programme.	• Groups of people can be underrepresented because of their geographical location and distance from people who have the power to make decisions. • Does the engagement represent the diversity and complexity of South Cumbria and Lancashire? For example, have people in coastal towns been engaged? • Could the HARRI van, as well as roadshows be used more effectively to visit more geographically diverse communities? • Were the only young people engaged with living in Blackpool? Could more work be done with groups beyond Blackpool? • Which rural communities were engaged with beyond farmers?

Opportunities for the LSCNHP

- Could local people be involved in asset mapping activities to map organisations, communities and knowledge?

- Could local people be hired to act as community links to the LSCNHP?

- Is there an opportunity to build more knowledge on what it means to engage in a diverse geographical location, particularly one where there are significant health inequalities from place to place?

- How might a programme like the LSCNHP deal with diverse local knowledge, which might conflict? How do they address the needs of the few and the many?

- Could engagement activities more effectively seek to find out more about local knowledge and local assets to aim to design facilities that reflect the local context?

- Could the LSCNHP do more to understand what is unique about health outcomes and accessing healthcare in a variety of geographical locations?

- How could the LSCNHP create stronger relationships and mutual understanding with local organisations in a variety of locations? Could links with local communities help to build local capacities (links with training and education)?

Ideas, Actions and Reflections from the LSCNHP

- Local knowledge.

- Could the LSCNHP and/or local NHS create strong relationships and mutual understanding with local organisations in a variety of locations?

- Political side.

- Be clear on why.

- Lots of interest in Central Lancashire regarding emergency department (A&E) provision in Chorley.

Education and Capacity Building

This section includes considerations for creating a collaborative culture through education and capacity building. Within the evidence base, mutual learning between both staff and participants is highlighted as central to effective engagement processes (Bonevski et al., 2014; Cyril et al., 2015; Holroyd-Leduc et al., 2016; Meakin et al., 2017). As part of an engagement approach, participants should be provided with opportunities to be involved in organising and facilitating engagement in formats that are easy to understand (Ekeziee tal., 2021), be provided with opportunities to build confidence, skills and opportunities to network (Kelleher, Seymour and Halpenny, 2014; Meakin et al., 2017). This could involve hiring members of the community to help support engagement (see Level of Involvement and Drawing on Local Knowledge) or generally involving members of the community to support engagement. There should also be opportunities for staff to build the skills required for inclusive engagement (Kilpatrick, 2009; Farooqi et al., 2018; Harrison et al., 2019).

Suggestions for education and capacity building

- Information on training in cultural competency is included in Farooqi, et al. (2018).

- Training for inclusive communication for both staff and service users, as discussed by Meakin et al. (2017).

- Disability equality training, inclusive involvement and awareness of the social model of disability, as discussed by Meakin et al. (2017).

- Personal development opportunities motivate people to become involved and can include training, skill development, being paid, and voluntary work. This can increase confidence, provide opportunities to network, increase self-worth and develop an awareness of services (Meakin et al., 2017).

- Find ways of accrediting participation (Meakin et al., 2017).

- Capacity building and training of both staff and participants can help sustain engagement approaches (Parnez and Martowicz, 2015).

- Kenny et al. (2008) emphasise the importance of engaging people in training in participation.

Education and Capacity Capacity Building for the LSCNHP

Current Practice	Comment and Questions for Practice
• Unclear if there were any opportunities for underrepresented people to build their capacity and confidence during engagement activities. • An emphasis was placed on 'educating' participants on the New Hospitals Programme, rather than mutual learning. LSCNHP disagree but would like to re-look at aims as they feel more communication orientated. LSCNHP questions 'How much prior knowledge do they have?' • During engagement activities, underrepresented people voiced the need for continuous investment in staff training, as well as raising their awareness with regard to the needs of specific groups. Suggestions included increased awareness of autism, mental health, equality, diversity, LGBTQ+, military veterans, prostate cancer, sickle cell, diabetes, and general customer service training.	• Is it possible for underrepresented people to be involved in organising and facilitating engagement? • Could they be hired to play a role in engaging with the community? • Can underrepresented people who participate in delivering the engagement activity be rewarded with certificates or other accreditation for their contribution? • Could opportunities to build skills and networks be built into the engagement activities? • What opportunities are there for staff to build skills in inclusive engagement?

Ideas, Actions and Reflections from the LSCNHP

• Explore opportunities on quality, inclusion and health inclusion training.

Resources

The theme 'resources' covers considerations for time, money, material, staff, and other resources that support engagement activities with underrepresented people. The evidence base highlights the importance of rewarding participants for their time and reimbursing them for the cost of attending engagement events, including travel costs in order to value people's time and support their attendance (Ministry of Health, 2016; Meakin et al., 2017; Farooqi et al., 2018; National Institute for Health Research, 2021; Batty, Humphrey and Meakin, 2022). This could include the provision of food at events, accreditation and certificates (NIHR INVOLVE, 2019). Allocating enough time to plan and deliver engagement activities is also highlighted as important for engaging underrepresented people (Holroyd-Leduc et al., 2016; Ministry of Health, 2016; Meakin et al., 2017). Engagement requires strategic planning with a clear purpose, outlining expectations, duration and outlining involvement. At the planning stage, enough time should be allocated to finding and building relationships with groups, giving sufficient notice and ensuring that engagement is accessible (Ministry of Health, 2016; Farooqi et al., 2018).

Suggestions for resources to support engagement

- Find ways of accrediting participation (Meakin et al., 2017). For example, giving credit on reports and papers, and holding events or awards for contributions (NHS England, 2016b).

- Pay people for their time and for expenses, such as travel, avoid making this too difficult (Ministry of Health, 2016; Farooqi et al., 2018; Ekezie et al., 2021; Batty, Humphrey and Meakin, 2022). See NIHR (2022) *Payment Guidance for Researchers and Professionals* including risks to welfare benefits.

- Have a single point of contact for service users to contact someone if they have a concern. Include text, phone and email (Meakin et al., 2017).

- Allocate funding for accessibility, expenses and rewards (Meakin et al., 2017).

- Consider whether funding for appropriate communication support, such as interpreters and translation services (Farooqi et al., 2018; NIHR INVOLVE, 2019).

- Meakin et al. (2017) have a list of systems to put in place, such as terms of reference for service users on page 9 of their [Shaping Our Lives report](#).

- When creating a stakeholder committee, consider a 'buddy system' between new and more experienced members on the committee to support participation (Kellerher, 2014).

- Carry out outreach work to reach people who do not normally participate and discover what is important to them (Kelleher, 2014).

- Plan for engagement with a clear purpose, expectations, duration and details of involvement (Ministry of Health, 2016; Meakin et al., 2017). This involves strategic planning (Holroyd-Leduc et al., 2016).

- Begin early and allow enough time to find groups, give sufficient notice and ensure the engagement is accessible (Ministry of Health, 2016). Allow enough time for real, genuine input from groups.

Resources for the New Hospitals Programme

Current Practice	Reflections and Questions for Practice
• Patient representatives are offered a voucher for their time. • Participants other than those acting as patient representatives are not currently offered any reimbursement (although some Healthwatch workshops took place online). • Participants are not currently offered a reward or accreditation for their time.	• Could more time be allocated for planning engagement activities, particularly those with underrepresented people who may have additional needs and preferences? • Could funding be allocated for accessibility costs, expenses such as travel and rewards acknowledging people's time? • Is it possible to recruit people in community champion roles to support engaging with the community? • Is funding for appropriate communication support provided for inclusion groups? • Is sufficient time allocated to find groups to communicate with, give sufficient notice and ensure the engagement is accessible?

Ideas, Actions and Reflections from the LSCNHP

• Explore opportunities for equality, inclusion and health inclusion training.

• Considering the recommendations/best practice guidance in planning and delivering or commissioning engagement activities (as it isn't necessarily always going to be us delivering the engagement, could be e.g. Healthwatch, ICB Engagement team etc.)

• It would be great to have a checklist of things to consider in the planning as part of a toolkit.

Beyond Traditional Methods

There should be a move beyond traditional engagement methods for engaging underrepresented people (Beresford, 2013). A diverse range of engagement approaches enables equality of opportunity within participatory activities (NHS England, 2016a). 'Meaningfully involving a diverse range of people in research means doing things differently' (Involve, 2012, p.4). Traditional methods include meetings, surveys and other methods that need writing or verbal skills (Beresford, 2013). However, written communication causes a barrier for some people (Young and Hunt, 2011; Farooqi et al., 2018). Engagement activities may be presented in a format or language that alienates some people (Kelleher, Seymour and Halpenny, 2014; Kenny et al., 2015) and may not be aligned with priorities in their lives (National Institute for Health Research, 2021). To move beyond traditional methods, consider flexible, creative approaches including visual and interactive resources (Involve, 2012; Parnez, 2016, Dusenbery, 2021) within effective strategies to engage people (Kelleher, Seymour and Halpenny, 2014). Alternative and creative methods can make engagement accessible and relevant to different needs (INVOLVE, 2012).

Suggestions for engagement that goes beyond traditional methods

- It is recommended that organisations shift away from formal and jargon-filled documents (NHS England, 2016b).

- Involving underrepresented groups is resource-intensive and challenging, but with sufficient funds, it is possible to develop creative approaches to engage all members of society (Bonevski et al., 2014).

- Unwin, Meakin and Jones (2020) describe using filmmakers to help disabled people in Gypsy, Roma and Travelling communities to share their stories.

- Healthwatch (2021) include details on creative and original approaches to engaging with seldom heard group, including mapping techniques, snap chat, co-production and video diaries. See 'Engaging Seldom Heard Groups in Healthwatch Research' (Healthwatch, 2021) for details.

- Kelleher, Seymour and Halpenny (2014) describe a variety of engaging methods that are both verbal and non-written, which are informal and therefore more likely to be engaging.

- Local Government Association (2019) provide details on a variety of engagement activities, including asset mapping.

- Consider activities that take positive action again discrimination (Latif, 2010).

- Larsson (2018) discusses methods where participants are more active in the process and able to express themselves in ways other than just verbal methods, active and expressed themselves in ways other than verbal ones, including drawing, painting, writing, theatre, photography, filming, workshops, storytelling, digital tools and mapmaking. These methods 'promote participants' sense of control and thereby enable them to take a more active part in the research process (p.16).

- The New Zealand Government provide various guides on community engagement, including support selecting methods for engagement for the various levels of the IAP2 Spectrum of engagement.

Beyond Traditional Methods for the LSCNHP

Current Practice	Comments and Questions for Practice
• The LSCNHP has identified twelve engagement mechanisms used to date. Two of these mechanisms are specifically for underrepresented people. • The programme's engagement mechanisms have has had to accommodate Covid-19 restrictions and guidance, which has included a high level of online activity. However, some face-to-face and telephone engagement was included. **Engagement with underrepresented people** • Healthwatch Together was commissioned to facilitate focus groups with underrepresented people and did so in two phases. • Healthwatch Together already have some established links with patients, the public and local networks. • Objective: for underrepresented people to share thoughts, hopes, fears and clinical benefits for hospital facilities and key themes. To educate on the LSCNHP and gather feedback. • Mostly online, 142 participants who were in 20 different community groups. • Healthwatch also carried out one-to-one interviews with some individuals to provide in-depth case studies. • The Communications and Engagement Oversight Group identified ten additional 'inclusion groups' to target through interviews with stakeholder representatives (people within community groups to speak on the behalf of the group). • Fifteen forty-minute interviews were conducted with individual stakeholders who represented patient and inclusion groups by LSCNHP. Group sessions also took place.	• The use of traditional methods may alienate underrepresented people. • Could more be done to avoid formal and jargon-filled documents? • Is it possible to develop an understanding of non-traditional methods that engage underrepresented people and how to implement them? • Look at current guidelines on engagement methods, including Community Engagement Methods from New Zealand Government and the UK Local Government Association. • Speak to underrepresented people about how they wish to be engaged and what they think works well. Involve underrepresented people in the planning, development and delivery of these methods. • Consider partnering with organisations that specialise in developing creative engagement and co-production methods.

Ideas, Actions and Reflections from the LSCNHP

• Not all formal documents.

• Would like to develop a further understanding of non-traditional methods that engage underrepresented people and how to implement those methods.

• Would like to unpack some methods.

• Could a patient representative or underrepresented people be involved in the planning, development and delivery of non-traditional methods? They know best and could help plan and deliver.

Accessibility

'Access is about providing people with equal opportunity to participate fully in whatever is being offered' (Meakin et al., 2017, p. 16). Considering accessibility involves finding ways to remove barriers to communication materials and participating in engagement activities. It is recommended that jargon is avoided (Beresford, 2013; Cowan, 2020), that people are asked how they would like to be referred to (Cowan, 2020), and that tests are run on materials such as questionnaires to ensure they are clear and present the right messages (Farooqi, 2018). Written language also causes problems for some underrepresented people (Young and Hunt, 2011; Parnez, 2016, Farooqi, 2018), which is why methods that do not rely on written communication are recommended.

Suggestions for accessibility

- Ministry of Health, New Zealand Government provides in detail information on how to make information accessible to different groups of disabled people.

- Provide accessible documents, check meanings and includes images to support any text (Ministry of Health, 2016).

- Barriers to participating may include transport and financial barriers (Beresford, 2013; Ekezie, 2021). For people with disabilities, this may be even more of a barrier.

- Farooqi (2018) includes information on accessibility for ethnic minority groups specifically. For example, the use of translators, the use of ethnic minority researchers and avoiding jargon.

- Ekezie et al. (2021) include ways in which to make sharing of outcomes more accessible

- Consider creating a record of who the people engaging are and what their accessibility requirements are to improve engagement (Meakin et al., 2017).

- Meakin et al.'s report for Shaping Our Lives (2017) has guidelines for how to make events accessible on page 21

- May be able to draw on and use the accessibility function on MS Word and Powerpoint to support the development of accessible resources. This includes the use of contrasting colours, making sure things can be read by screen readers and including alt text for images.

- Accessibility guidance for websites and apps.

Accessibility on the New Hospitals Programme

Current Practice	Reflections and Questions for Practice
LSCNHP team have the following available: • Easy Read versions are available on request. • British Sign Language version of the LSCNHP introductory video. • Materials in different print formats and languages on request. • Further information summary documents in plain English. • All digital materials at AA standard as stipulated in the WCAG Version 2.1 and aim to pass higher world-leading AAA wherever possible.	• Is jargon sufficiently avoided? • Are barriers to engagement sufficiently addressed? • Are people asked what they need to support their participation? • Could there be an exploration of methods and communication that goes beyond written communication?

Ideas, Actions and Reflections from the LSCNHP

• Jargon is not felt to have been sufficiently avoided.

• Action – to ask people what they need to support their participation.

• Action – be more direct in questions around accessibility. Be sure to LSCNHP understand the needs and can adapt.

• Develop communications and engagement approaches with accessibility in mind.

Tailoring and Combining

Using a variety of different methods helps reach diverse groups of people with different communication preferences (NHS England, 2016; NHS England, 2017; Dusenbury, 2021; Ekesie, 2021; Healthwatch, 2021). One size does not fit all even within particular identified groups (Parnez and Martowicz, 2015; Ministry of Health, 2016; Unwin, Meakin and Jones, 2020). A range of approaches is needed to allow for equality of opportunity (NHS England, 2016). Ask people how they prefer to communicate and be engaged (Young and Hunt, 2011; Parnez and Martowicz, 2015; Holroyd-Leduc et al., 2016; NHS England, 2016a). Ask groups to check materials to ensure they are appropriate and communicate the right messages (Healthwatch, 2021). People have communication difficulties for a wide range of reasons and individual communication needs differ. For example, people may have difficulty understanding information, difficulty responding, difficulty responding and difficulty reading body language. It is important to take time to understand how to respond.

Suggestions for tailoring and combining

- Methods used must be targeted and aligned to the specific needs and preferences of underrepresented people to facilitate meaningful participation (Kelleher, 2014).

- 'Successful engagement adapts to the condition, state, capability and background of those engaged, but also to the engagement process' (Holroyd-Leduc et al., 2016).

- Combine different methods to reach people with different preferences (Healthwatch, 2021).

- Include flexible engagement options and a broad range of approaches (Ekezie et al., 2021).

- Ask participants how their involvement could be improved (Meakin et al., 2017).

- Make methods tailored to different groups and projects (Flynn, Walton and Scott, 2019; Batty, Humphrey and Meakin, 2022).

- Adapt the methods to the health condition, state, capability and backgrounds of people (Holroyd-Leduc et al., 2016).

- There is a range of social and technical barriers to different communication methods. No single form of communication is suitable for all of the participants. Digital platforms are suitable for some but are barriers to others (Changing Lives and Centre for Public Impact, 2020).

- Ask people what they need to be able to participate, including support and interpreters (Parnez and Martowicz, 2015; Holroyd-Leduc et al., 2016).

Tailoring and Combining on the New Hospitals Programme

Current Practice	Reflections and Questions for Current Practice
• The LSCNHP state that engagement mechanisms have been 'tailored to the communication preferences and needs of each target audience'.	• Could a bank of methods that could be tailored to the needs and combined in different ways be created? Or a different approach? • Could participants involved be asked how to improve the engagement methods and if the messages are conveyed correctly? • Could people be asked what they need to be able to participate, including support and interpreters?

Ideas, Actions and Reflections from the LSCNHP

• Participants to be involved in improving engagement methods and checking to see if messages have been conveyed correctly.

• Action - Ask participants if they have any accessibility requirements/tailor approach and materials to the audience (e.g. adapting content)/ask for feedback on how we could improve.

• Consider including a checklist in the future toolkit.

Sustainability

'…participation needs to progress beyond one-off, discrete activities, to become an on-going embedded process' where underrepresented people are 'listened to and enabled to effect change within services and organisations' (Kelleher, Seymour and Halpenny, 2014, p. 54). A large proportion of the evidence base back aiming for embedded and continuous engagement, which is particularly crucial for building and maintaining meaningful relationships with community organisations and groups of people (Latif, 2010; Parnez and Martowicz, 2015; Holroyd-Leduc et al., 2016; Local Government Associate, 2019).

An embedded approach to engagement can support the creation of services that are more likely to endure strain, the development of processes and resources and pilot testing (Kenny et al., 2015; Local Government Associate, 2019). Engagement can be sustainable beyond the immediate project, contributing to community liveability, creating strengthened social connections, and contribute to spaces, growth and prosperity.

Creating the conditions for sustainable engagement involves embedding engagement evaluation, practice and training (Parnez and Martowicz, 2015) into the organisation. Public decision-making bodies are likely to reflect on the volume of engagement activity, rather than the impact that activity generated (Kelleher, Seymour and Halpenny, 2014). It is recommended that organisations go beyond numbers and cost-benefit, evaluating the social, strategic and economic value of culture change (Local Government Associate, 2019). Evaluation, which includes asking people for feedback and ideas for how to improve engagement and making adjustments accordingly can be a 'game changer' (Meakin et al., 2017).

Further Information on Sustainability

- The Local Government Association (2019), Meakin et al. (2017) and Kelleher, Seymour and Halpenny (2014) all offer suggestions for evaluating engagement.

- The New Zealand Ministry of Health (2016) provide a list of questions to consider for evaluating engagement with underrepresented groups.

Ideas, Actions and Reflections from the LSCNHP

- Sustainability beyond (or connected to) hospital proposals e.g. community liveability (the degree to which a place is good for living in), social connections, community spaces, growth and prosperity is an area the LSCNHP would like to explore further.

- Seek feedback on engagement and use this to improve activities going forward, sharing learnings with wider local LSCNHS.

Sustainability for the New Hospitals Programme

Current Practice	Reflections and Questions for Practice
• Evaluation currently takes place within the LSCNHP team and with engagement delivery partners, for example, Healthwatch.	• How could engagement with underrepresented groups become an ongoing and embedded process? • How could the LSCNHP create sustainability for underrepresented groups beyond feedback on hospital proposals? For example, how can it contribute to community liveability, social connections, community spaces, growth and prosperity? • How might the LSCNHP evaluate the quality and impact of engagement beyond numbers? For example, any social, strategic and economic value produced, if possible?

Anticipated Benefits and Effects of the Project Activities

The anticipated benefits of the project include an improved approach to engagement with underrepresented people and the wider community through the Lancashire and South Cumbria New Hospitals Programme, as well as learnings that could be transferred to other transformation programmes both locally and nationally. It is anticipated that specific changes to engagement practice will be made in areas including accessibility, engagement mechanisms and activities and meaningful feedback following engagement.

The LSCNHP is one part of a complex health and care system, and a benefit of undertaking such projects is this means the learnings go beyond the NHP. As the new Integrated Care System (ICS) becomes established, the framework developed in this project is equally as relevant and transferrable to the engagement activities of all partners within the health and care system. The more the NHP (and other partners in our health and care organisations) understand, the greater the opportunity for everyone to benefit.

The outputs from this project mean the programme has the opportunity to hear from not only more people but a much wider range of people and perspectives. In turn, this leads to better decision-making on the NHP, both regionally and potentially nationally. In doing so it is hoped this not only assures the LSCNHP decision-makers, it brings confidence to our staff, patients, potential patients and population.

It is hoped the learnings of this project can be used to influence engagement undertaken in New Hospital Programmes schemes across the county and also the national New Hospital Programme. Finally, it is hoped that people from underrepresented groups take a real sense of value from this work and their very welcomed continued input to the Lancashire and South Cumbria New Hospitals Programme.

Next Steps

The findings from this project will be used to inform future engagement plans for the Lancashire and South Cumbria New Hospitals Programme. Learnings will also be shared with other programmes and partner organisations.

Additionally, this project has served to consolidate the relationship that we have with the New Hospitals Programme, which provides the platform for a planned series of workshops to develop a research project pipeline. The first two of these were held in September and December 2022, which brought together academics from across the university with colleagues in the New Hospitals Programme to develop fundable research areas and questions on the theme of Sustainability.

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References

Arnstein, S. R. (1969) 'A Ladder Of Citizen Participation', Taylor & Francis Group, 35(4), pp. 216-224
https://www.tandfonline.com/doi/abs/10.1080/01944366908977225

Batty, G., Humphrey, G. and Meakin, B. (2022) Creating better lives for all by involving Disabled people and service users. Shaping Our Lives National User Network Community Interest Company Tickboxes and Tokenism? Service User Involvement Report 2022. Available at: https://shapingourlives.org.uk/wp-content/uploads/2022/02/Tickboxes-and-Tokenism-Feb-2022.pdf

Beresford, P. (2013) Beyond the usual suspects. Towards inclusive user involvement. London. Available at: https://lx.iriss.org.uk/content/beyond-usual-suspects-towards-inclusive-user-involvement

Bonevski, B. et al. (2014) 'Reaching the hard-to-reach: A systematic review of strategies for improving health and medical research with socially disadvantaged groups', BMC Medical Research Methodology. BioMed Central Ltd., 14(1), pp. 1–29. doi: 10.1186/1471-2288-14-42/TABLES/5.

Changing Lives and Centre for Public Impact (2020) Learning to Listen Again How people experiencing complex challenges feel about engagement and participation through the Covid-19 pandemic. Available at: https://www.centreforpublicimpact.org/assets/documents/learning-to-listen-again.pdf

Cyril, S. et al. (2015) 'Exploring the role of community engagement in improving the health of disadvantaged populations: a systematic review', Global health action. Glob Health Action, 8. doi: 10.3402/GHA.V8.29842.

DHSC (2021) Eight new hospitals to be built in England. Available at: https://www.gov.uk/government/news/eight-new-hospitals-to-be-built-in-england

Ekezie, W. et al. (2021) 'Patient and public involvement for ethnic minority research: an urgent need for improvement', Journal of the Royal Society of Medicine. J R Soc Med, 114(7), pp. 347–350. doi: 10.1177/0141076821994274.

EMAHSN (no date) EMAHSN top tips for patient and public involvement Involving Black, Asian, and minority ethnic (BAME) communities with long term health conditions. Available at: https://emahsn.org.uk/images/resource-hub/PPI%20documents/Top_tips/Involving_Black_Asian_and_Minority_Ethnic_BAME_Communities.pdf

Farooqi, A. et al. (2018) Toolkit for: Increasing participation of Black Asian and Minority Ethnic (BAME) Groups in Health and Social Care Research. Available at: https://arc-em.nihr.ac.uk/clahrcs-store/increasing-participation-black-asian-and-minority-ethnic-bame-groups-health-and-social

Flynn, R., Walton, S. and Scott, S. D. (2019) 'Engaging children and families in pediatric Health Research: A scoping review', Research Involvement and Engagement. BioMed Central Ltd., 5(1), pp. 1–8. doi: 10.1186/S40900-019-0168-9/TABLES/4.

Harrison, J. D. et al. (2019) 'Patient stakeholder engagement in research: A narrative review to describe foundational principles and best practice activities', Health expectations : an international journal of public participation in health care and health policy. Health Expect, 22(3), pp. 307–316. doi: 10.1111/HEX.12873.

Healthwatch (2021) Engaging seldom heard groups in Healthwatch research. Available at: https://network.healthwatch.co.uk/guidance/2021-04-26/engaging-seldom-heard-groups-healthwatch-research

Holroyd-Leduc, J. et al. (2016) 'Giving voice to older adults living with frailty and their family caregivers: engagement of older adults living with frailty in research, health care decision making, and in health policy', Research involvement and engagement., 2(1). doi: 10.1186/S40900-016-0038-7.

INVOLVE (2012) Diversity and inclusion: What's it about and why it is important for public involvement in research. Hampshire. Available at: https://www.invo.org.uk/wp-content/uploads/2012/10/INVOLVEDiversityandInclusionOct2012.pdf

Kelleher, C., Seymour, M. and Halpenny, A. M. (2014) Promoting the Participation of Seldom Heard Young People: A Review of the Literature on Best Practice Principles Review of the Literature on Best Practice Principles. Dublin. Available at: https://arrow.tudublin.ie/cgi/viewcontent.cgi?article=1026&context=aaschsslrep

Kenny, A. et al. (2015) 'Community participation for rural health: a review of challenges', Health Expectations., 18(6), pp. 1906–1917. doi: 10.1111/HEX.12314.

Kilpatrick, S. (2009) 'Multi-level rural community engagement in health', The Australian Journal of Rural Health., 17(1), pp. 39–44. doi: 10.1111/J.1440-1584.2008.01035.X.

Larsson, I. et al. (2018) 'Children and young people's participation in developing interventions in health and well-being: a scoping review', BMC health services research., 18(1). doi: 10.1186/S12913-018-3219-2.

Latif, S. (2010) Effective methods of engaging black and minority ethnic communities within health care settings. London. Available at: https://raceequalityfoundation.org.uk/health-and-care/effective-methods-of-engaging-black-and-minority-ethnic-communities-within-health-care-settings/

Local Government Associate (2019) New Conversations 2.0 - Local Government Association Guide to Engagement . Available at: https://www.local.gov.uk/publications/new-conversations-20-lga-guide-engagement

Meakin, B. et al. (2017) Improving Understanding of Service User Involvement and Identity - A Guide for Disabled People who are Interested in being a Service User Representative., Available at: https://shapingourlives.org.uk/report/improving-understanding-of-service-user-involvement-and-identity-a-guide-for-disabled-people-who-are-interested-in-being-a-service-user-representative/

New Zealand Ministry of Health (2016) A Guide to Community Engagement with People with Disabilities A Guide to Community Engagement with People with Disabilities (2nd edn). Wellington: Ministry of Health. Available at: https://www.health.govt.nz/publication/guide-community-engagement-people-disabilities

NIHR (2021) A practical guide to being inclusive in public involvement in health research: Lessons learnt from the Reaching Out programme. Available at: https://www.learningforinvolvement.org.uk/?opportunity=nihr-reaching-out-a-practical-guide-to-being-inclusive-in-public-involvement-in-health-research-lessons-learnt-from-the-reaching-out-programme

NIHR INVOLVE (2019) Being Inclusive in Public Involvement (PI) in Health Research. Available at: https://www.invo.org.uk/wp-content/uploads/2019/02/Being-Inclusive-Health-Research.pdf

NHS England (2016a) Guide 06: A bite-size guide to Improving deafblind patient and carer public voice in the NHS. Available at: https://www.england.nhs.uk/wp-content/uploads/2016/07/bitesize-guide-improv-deaf-ppv-nhs.pdf

NHS England (2016b) The NHS Youth Forum Top Tips To Involve Young People in Healthcare Planning. Available at: https://www.byc.org.uk/wp-content/uploads/2016/09/NHS-Youth-Forum-Tip-Brochure-FINAL.pdf

NHS England (2017c) Patient and public participation in commissioning health and care: statutory guidance for CCGs and NHS England. Available at: https://www.england.nhs.uk/publication/patient-and-public-participation-in-commissioning-health-and-care-statutory-guidance-for-ccgs-and-nhs-england/

Parnez, T. and Martowicz, A. (2015) How to Engage with Ethnic Minorities and Hard to Reach Groups. Glasgow. Available at: https://bemis.org.uk/wp/wp-content/uploads/2013/10/how-to-engage-em-htr-groups.pdf

Rowe, G. and Frewer, L. J. (2005) 'A Typology of Public Engagement Mechanisms" The Concept and Enactment of Public Participation'. doi: 10.1177/0162243904271724.

Singleton, J., Jones, G. and Hanumantha, S. (2017) 'Deaf community involvement in the research process: An examination of barriers and strategies in research in deaf education', in Cawthon, S. and Garberoglio, C. Lou (eds) Research in Deaf Education: Contexts, Challenges, and Considerations. Oxford University Press, pp. 75–92. doi: 10.1093/OSO/9780190455651.003.0004.

Tritter, J. Q. and McCallum, A. (2006) 'The snakes and ladders of user involvement: Moving beyond Arnstein', Health Policy. Elsevier, 76(2), pp. 156–168. doi: 10.1016/J.HEALTHPOL.2005.05.008.

Unwin, P., Meakin, B. and Jones, A. (2020) Including the Missing Voices of Disabled People in Gypsy, Roma and Traveller Communities Final Report. Available at: https://www.drilluk.org.uk/wp-content/uploads/2020/12/Missing-Voices-FINAL-report.pdf

Urban Institute (2021) Strategies for Including Deaf and Hard of Hearing Participants in Research | Urban Institute, Urban Wire. Available at: https://www.urban.org/urban-wire/strategies-including-deaf-and-hard-hearing-participants-research

Win Win Alliance (2021) Essential Elements for Effective Involvement and Co-Production. Available at: https://shapingourlives.org.uk/wp-content/uploads/2021/08/WWA-Essential-elements-for-effective-co-production-19.3.19-final.docx.

Young, A. and Hunt, R. (2011) Research with d/Deaf people. Manchester. https://research.manchester.ac.uk/en/publications/research-with-ddeaf-people.

Appendix 1: Conversations with Stakeholders Involved in Delivering Engagement

Healthwatch

The Lancaster University team and LSCNHP Communications Workstream Project Manager, Louise Barker, had a conversation with the Director of Healthwatch Lancashire, Kerry Prescott to further discuss engagement with underrepresented people through the LSCNHP programme. The outcomes of the conversation were validated by the wider Healthwatch Lancashire team. The conversation highlighted:

- It takes considerable time to find and maintain relationships with community groups.

- Healthwatch's view is that relationships with community groups are two-way. In return for engagement, Healthwatch tries to find out if there is anything they can assist the groups with, such as signposting to services.

- Healthwatch tries to tailor methods to the groups by speaking to group leaders to find out how they engage.

- Examples of effective methods that can put people at ease include participants being asked to raise their hands or stand up to indicate if they agree with or disagree with something, the use of whiteboards, sticky notes and Google Jamboard.

Challenges of Engaging with Underrepresented People

- Evaluating what the participants gained from taking part is a gap. One of the challenges here is that people have limited time to engage further.

- Finding groups, which have changed due to Covid.

- Feeding back after the engagement on the changes made as a direct result is a significant challenge.

- People often feel tired of being engaged and do not think anything will happen as a result.

Healthwatch Reflecting on the New Hospitals Programme Engagement

- There was limited time between phases to set up relationships and prepare.

- Covid restrictions caused difficulties.

- The Healthwatch team and the LSCNHP reflected on what worked and what did not together.

Appendix 2: Conversations with Stakeholders Involved in Delivering Engagement

Communications and engagement consultancy

The Lancaster University team and Louise Barker also had a conversation with three practitioners from a communications and engagement consultancy involved in conducting interviews with representatives of community groups. The conversation highlighted:

Cynicism and Disillusion

- All groups feel they have heard before that new hospitals will be built that will be inclusive of their needs and are therefore cynical.

- All groups had negative experiences with visiting hospitals. For example, young carers were overlooked whilst their parent was in hospital and refugees were refused treatment.

- There was cynicism that so much money is going to be spent on new hospitals when it can take so long to be seen by a healthcare professional.

- 'One of the reasons people are hard to reach is because they believe participation won't make a difference.'

Deaf Community

- The challenges experienced by the d/Deaf community were surprising to the researchers.

- Written English is difficult for the community to understand – for example cannot read hospital letters, hard to find help to make appointments.

- Staff training and translators are needed.

- Empathy and understanding over facilities.

Communication, signage, buildings

- Long corridors and poor signage.

- Training staff to better understand disabilities and improved clinical records, improved wi-fi 'Life-line for Deaf and Blind community'.

- Struggling with signage if Blind and d/Deaf.

Written Language

- 'Too much reliance on written language, full-stop' (Communications and engagement consultancy Practitioner).

- The assumption is that everyone has a high level of understanding.

- Need more maps and pictures.

- The average reading age in the region is 11 years old by the communications and engagement consultancy. Infact, the [The National Literacy Trust](#) state that 14.9% of adults in England have literacy levels at or below Entry Level 3, which is equivalent to literacy skills expected of a nine to eleven year old.

- Hospital letters are a challenge.

Reaching Groups

- Challenging to speak to groups because they are often run by volunteers who have other priorities.

- Reaching them is more than an email, need to build relationships through meetings, networks and social media.

- Healthwatch influenced different methods of communication, including whether it was online or not.

- The LSCNHP provided Healthwatch with an easy-read version of the case for change, which was requested and used. For example, groups with social anxiety prefer to read bios online before meeting the researcher and being online provides the option to type responses.

- Surprising how many groups they managed to reach online.

- Limited phone numbers were available for contacting the groups.

- User reps were contacted, some took the questions to groups and the interviewers gained more insight if the user rep just spoke from their experiences.

Continuing Engagement

- The communications and engagement consultancy recommended that in the future participants should be sent a thank you email with updates on the progress of the information collected.

Appendix 3: Engagement Mechanisms that were not targetted specifically at underrepresented people

Market Research Interviews

- Targeted at the public on an individual basis.

- Utilised the 'Market Research Society Code of Conduct and best practice principles'.

- Involved one-off engagement but participants could choose to complete further surveys.

- Interviews on the phone, in-person, and online as part of two waves.

- Public polling through a market research agency, creating a baseline of public sentiment towards current services among a demographically representative sample of the public (with quotas by age, gender and postcode, located within core Clinical Commissioning Group (CCG) areas.

- Mixed methods approach for optimal accessibility. Face-to-face is more effective for younger audiences and telephone more effective for older and more remote audiences.

Online Surveys – 'Case for Change'

- Targeted at the public and members of staff on an individual basis.

- Participants were invited to share views on the Case for Change, agreeing or disagreeing with each theme.

- The survey attracted a large about of people aged over 65, as well as females and those who were white.

- An unintended impact may be that a lot of the comments were around lack of detail on proposals, evidence on new hospitals and dissatisfaction with wider problems facing NHS.

Big Chat

- The Big Chat Platform was a website and online conversation for crowdsourced conversation to enable participants to share hopes, fears and desires for facilities, as well as engage with one another. The website was used at multiple points in the process to collect views (Case for Change to longlist stages).

- Big Chat targeted staff, Foundation Trust members, voluntary, community, faith and social enterprise sector (VCFSE) reps; patient reps.

- Staff from ethnic minority groups were underrepresented. Efforts were made to engage with them separately.

- Staff aged 25 were also underrepresented

- People responded well to Big Chat as a safe space for questions and answers.

- Participants highlighted the importance of findings from local people being incorporated throughout the process to inform and shape final proposals.

- Participants had an expectation something will be done with their responses and they will be taken seriously.

Healthwatch Together Roadshows

- Healthwatch Together was commissioned to facilitate the first phase of public and patient engagement with a particular focus on underrepresented people and health inclusion groups. Healthwatch Together (HWT) consists of Healthwatch Blackburn with Darwen, Healthwatch Blackpool, Healthwatch Cumbria and Healthwatch Lancashire, working in collaboration together.

- The roadshows included face-to-face conversations at 16 public roadshow events in locations with high footfall, including towns and markets. Priority areas included Preston, Lancaster, Chorley and Barrow-in-Furness.

- Engagement included branded banners and flyers, paper copies of a survey and Healthwatch and LSCNHP staff and volunteers to guide people through a survey.

- The aim was to 'generate and maintain interest through strong community presence'.

- The roadshow visited supermarkets, markets, bus station, town centre locations, a college, a school car park, a housing estate (Kendal), one Hindu community centre, three with the Lancashire and South Cumbria NHS Foundation Trust (LSCFT) HARRI van (a mobile health information van, which visited Preston Market, Lancaster Sainsburys and a school in Kendal).

- Roadshow events included weekend and evening events for accessibility.

- The following information was recorded from participants: postcode, how participants describe where they live (town, village), age range, how they relate to the LSCNHP, gender, pregnancy, relationship status, disability, long-term illness or health condition, caring responsibilities, ethnicity, religion, sexual orientation, transexual or transgender, UK armed forces.

- Focus on the longlist of proposals, what people liked and did not like, their reasonings, and demographic questions also asked.

- Preston Bus Station was an effective location for engaging people from a lower socioeconomic background, families and older people.

- There was a low engagement at a school and bus stop in Kendal, as well as at a Fresher's Fair for students.

- Most participants claimed to be unaware of the LSCNHP before engagement, which is believed to indicate that this was an effective means of expanding reach to those who were unaware of the programme.

- Seldom-heard groups were noted to be more sensitive to changes to location and services.

- Participants indicated that there was an issue with 'not paying attention to nuanced needs of different user groups'.

Colleague Summits

Four dedicated summits are open to all staff.

Communication

Advertising campaign (print, online and radio), use of Facebook and Twitter, a website with blogs and other information on the programme and a communications campaign through media releases and other communication channels.

Patient engagement

Leaflets and posters with QR codes distributed to patients in hospitals and pop-up engagement in a hospital setting.