

Involvement and engagement framework

The ambition of Hertfordshire and West Essex Integrated Care System (ICS) to tackle health inequalities and improve health and care for residents will only be achieved if we place our people and communities at the heart of the decisions we take.

Developed from the ICB's *Working with People and Communities Strategy*, this involvement and engagement framework outlines how the NHS Hertfordshire and West Essex Integrated Care Board (ICB) will work with partner organisations in our integrated care system to ensure that our diverse people and communities are involved in priority-setting and decision-making forums.

This document includes:

- a structure to help people and communities see how their views, experiences and expertise can play a part in formal and informal health and care involvement and engagement
- a description of the tools available to the system to involve people, including co-production
- a description of how to resource involvement and engagement so that we can successfully deliver on working with people and communities.



Contents

| | |
|--|----|
| Introduction and context | 3 |
| Putting involvement and engagement into practice | 5 |
| Training and development | 11 |
| The toolkit for involvement and engagement | 12 |
| Using insight and data | 12 |
| Appendix 1: Our legal duties | 13 |
| Appendix 2: Draft Working with People and Communities Strategy (weblink) and NHS England Guidance on Working with People and Communities (weblink) | 14 |
| Appendix 3: Terminology | 15 |
| Appendix 4: Engagement Maturity Model | 16 |



Introduction and context

Involvement and engagement should guide all our work, from neighbourhood and community health and care discussions, to developing and commissioning new services and strategies at our most senior decision-making bodies.

This framework is based on the 10 principles outlined in the ICB's *Working in Partnership with People and Communities Strategy* (Appendix 2), which are [set out by NHS England](#) in national guidance to help organisations realise the benefits of working with people and communities. These principles are embedded into the ICB's constitution and have been adopted by the Hertfordshire and West Essex Integrated Care Partnership.

The principles are:

- centre decision-making and governance around the voices of people and communities
- involve people and communities at every stage and feed back to them about how it has influenced activities and decisions
- understand your community's needs, experiences, ideas and aspirations for health and care, using engagement to find out if change is working
- build relationships based on trust, especially with marginalise groups and those affected by health inequalities
- work with Healthwatch and the voluntary, community, faith and social enterprise (VCFSE) sector
- provide clear and accessible public information
- use community-centred approaches that empower people and communities, making connections to what works already
- have a range of ways for people and communities to take part in health and care services
- tackle system priorities and service reconfiguration in partnership with people and communities
- learn from what works and build on the assets of all health and care partners – networks, relationships, and activity in local places.

Developing our approach to public involvement and engagement

Our approach puts what NHS England calls a 'Start With People' focus at the centre. Organisations are encouraged to take this approach across all involvement and engagement activity. This diagram shows how it can be at the centre of planning:





The development of the ICB's *Working with People and Communities Strategy* involved different stakeholders and health and care professionals, patient voice members, representatives from the VCSFE Alliance and Healthwatch Hertfordshire and Healthwatch Essex representatives.

A task and finish group of experienced patient voice volunteers have helped to develop this Involvement and Engagement Framework, taking into account:

- the legacy of the three former clinical commissioning groups and the relationships, networks and activities which exist across the ICS
- the positive involvement and engagement practices which have, in many cases, been strengthened by the COVID-19 pandemic
- health and care inequalities and barriers to community involvement
- how people listen, give feedback and share information with the ICB.

Patient voice volunteer Alan Bellinger, a member of the Healthwatch Hertfordshire Board, has supported the group's work by writing a networking model from a volunteer perspective. This document includes some principles that Alan set out. The group will continue working with the ICB's Communications and Engagement Team to support the next steps and activities described in this document.

Building this framework has also considered:

- the involvement and engagement forums established in our ICB's health and care partnerships (HCPs)

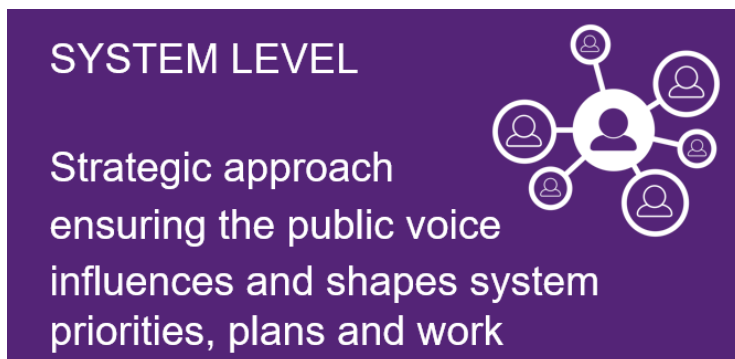
- how engagement and experience staff work can work effectively with partner organisations to increase efficiency and support innovation.

Thank you to everyone who has been involved in this work before and since the transition to a statutory ICS. This framework is open to review as our integrated care system beds in during 2022/23, to ensure it is fit for purpose and is aligned with the principles of the *Working with People and Communities Strategy*.

Putting involvement and engagement into practice - assurance

- The ICB must ensure legal and mandatory guidance on working with people and communities is adhered to when it carries out its duties, and that good practice is consistent. The ICB has already adopted governance arrangements which enshrine engagement in its constitution
- an agreed approach to working in partnership with people and communities.

The NHS England ‘people and communities’ guidance is to use a ‘System’, ‘Place’ and ‘Neighbourhood’ approach to turn these commitments into action. This helps to ensure that engagement and involvement influences decision making at the most appropriate level in our ICB and supports the flow of information and learning gained through engagement around the integrated care system.



At System level, there are mechanisms in place to give assurance that involvement and engagement work is ongoing, effective and influences decision-making, and that organisations’ responsibilities for working with people and communities are being delivered:

Joint Strategic Needs Assessments are prepared by local authorities through their Health and Wellbeing Boards with local ICBs, with the involvement of local Healthwatch, local people and district councils.

Joint local health and wellbeing strategies are prepared by local authorities, through the Health and Wellbeing Boards with local ICBs, with the involvement of local Healthwatch and local people.

Integrated care strategies are prepared by Integrated Care Partnerships, with the involvement of local Healthwatch and local people.

Joint forward plans are prepared by ICBs and partner NHS trusts and NHS foundation trusts, with the involvement of local people and Health and Wellbeing Boards.

Based on the committee structure of the ICB, an over-arching Patient Engagement Forum is proposed as an advisory group to the Board, with public participation sub-groups supporting the Primary Care and Nursing and Quality directorates. The communications and engagement team will continue to work with a range of stakeholders and patient and public voice representatives on projects and workstreams and will support a new network of diverse patient voice partners who will feed information and knowledge around the system and encourage very local community engagement champions to link together (see Appendix 4). Former CCG patient voice members would be invited to be part of this network, many of whom have continued to work closely with the ICB since its establishment in June 2022.

The Patient Engagement Forum is an advisory and steering group directly accountable to the ICB Board. It will have:

- one ICB executive and one non-executive member
- a patient voice volunteer chair
- representatives from the ICB's Primary Care and Nursing and Quality public participation sub-groups
- relevant 'experts by experience' – invited to attend the forum on an ad-hoc basis to contribute their views when a topic they have an insight into is being discussed
- Patient and public voice partners from the Health and Care Partnerships
- ICB Equalities Lead(s)
- carer representatives
- Healthwatch representatives.

The forum will meet formally, but will involve activity between meetings (e.g. sense-checking engagement and involvement activity for projects).

The learning from this forum will inform the Board's work and improve decision-making. There will also be an expectation that relevant individual experiences are considered when decisions are made, with 'experts by experience' invited to share their insights during Board meetings.

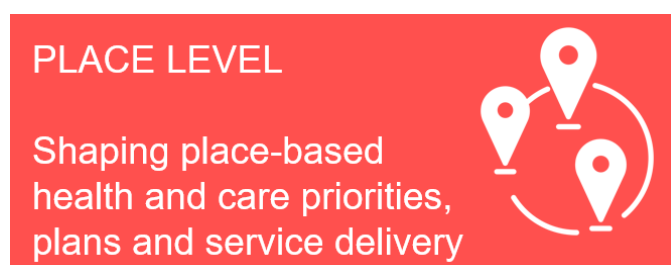
The ICB will also:

- ensure public involvement in and engagement on projects and programmes led by clinicians and health and social care professionals continue to support an advisory 'Readers Panel' to sense-check public-facing documents and ensure that they are accessible
- run a social media-based involvement network for anyone registered with a GP to join, where continuous involvement can be demonstrated, and where ideas can be shared and opportunities shared
- continue to distribute and grow the readership of our regular e-newsletter for the public which includes updates and raises awareness of opportunities to be involved and engaged with local NHS services
- help develop an Engagement Network for ICS staff who run non-ICB patient and carer experience forums (e.g. PALs team coordinators, provider trust public engagement and experience colleagues, etc.).



Both the ICB and ICP meet in public, with information about the meetings including the agenda and papers published in advance on accessible public-facing websites. Meeting papers will be made available in a timely way, and there will be clear information on how the public can pose questions and observe meetings if they want to.

The ICB's independent, non-executive members will be supported to undertake their roles through training and development. They will be tasked with helping to ensure that the statutory duties of the ICB are met, including those relating to patient and public participation, and will be connected with representative organisations including the new ICS-wide VCSFE Alliance, Health Care Partnership-specific citizens panels and the well-established and effective co-production groups in our area, including those run by Essex and Hertfordshire County Councils.



NHS England guidance describes the areas formerly served by Clinical Commissioning Groups as 'Places'. Places typically have populations of between 250,000 - 500,000 residents. We have three in our ICS, these are: south and west Hertfordshire, west Essex and east and north Hertfordshire. Each of these geographies is served by an acute trust – the West Herts Teaching Hospitals Trust in south and west Hertfordshire, Princess Alexandra Hospital in west Essex and the Lister Hospital in east and north Hertfordshire.

Health and care, public sector and voluntary and community organisations should engage with the communities in the places where they provide services, so that they can learn from those communities and start to tackle the health inequalities that affect residents together. These include challenges relating to housing, the built and natural environment, transport, economic opportunities and access to health and care services.

Each of our 'Places' has an established health and care partnerships (HCP), and there is an additional health and care partnership which serves people with mental health needs, learning disabilities and autism living in Hertfordshire.

Three health and care partnerships have involvement groups already in place. Each area has a different name for their main engagement and involvement forum (East and North Hertfordshire HCP has a Community Assembly, West Essex HCP has a Community Voices Group and South West Hertfordshire HCP has a Co-Production Board) and they operate differently in each place. Below are some examples of some of the progress already achieved by the involvement groups:

West Essex HCP Community Voices Group

An extensive engagement exercise in the pandemic built deeper connections with faith and ethnic minority groups to tackle misinformation about the COVID jobs, and regular information was cascaded to the communities around other issues and opportunities, such

as flu vaccinations and health inequalities.

Much of this was done collaboratively with volunteer and community groups, councils and the Citizens Advice Bureau and by raising the profile of health initiatives by attending events run by partner organisations.

South West Hertfordshire HCP co-production

SWHHCP's interim co-production board meetings began in September 2022, with the full board due to launch in April 2023.

The board has been reviewing transformation projects the HCP has already been working on, such as the virtual hospital, well-leg service, MSK transformation etc. Project leads outline their work and engagement and coproduction then received feedback from the board about engagement/coproduction to-date and recommendations.

In preparation for April 2023, when the board will be fully launched, elements being considered include appropriate public voice representation. At the moment, there are two patient representatives on the interim coproduction board, in addition to representatives from several organisations.

East and North Hertfordshire Community Assembly

The Assembly was launched in 2021 and is an online meeting held four times a year.

It is a forum for patients, carers, groups and members of the public from across the area who want to be informed and engaged and help shape and improve their local health and care services.

The Assembly wants to understand the challenges, needs, and views of residents, enable them to play a crucial role in the development of health and care services in the area, and act as a 'one stop shop' to enable the community to help the partnership achieve their objectives.

Representation from the community includes patient representatives mainly drawn from primary care networks, as well as VCSFE colleagues. Colleagues from ICS organisations also attend, and in 2022 the attendance invite was extended to the general public meaning anyone is able to join an Assembly meeting online.

Over time, these different models are expected to learn from each other and share best practice, developing and evolving.

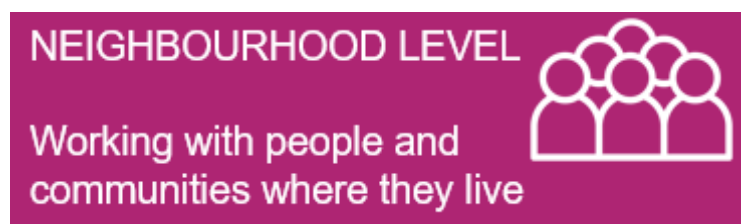
Each provider organisation which is a member of an HCP (HPFT, HCT, GP practices, Hertfordshire or Essex County Council, CLCH etc.) also has their own established, long-running patient and/or public engagement forums.

Involvement and engagement should be joined up, not duplicated. There will be a representative from each place-based forum and the mental health, learning disability and autism HCP on the System level Patient Engagement Forum, ensuring a link between Place and System.

The ICB's communications and engagement team will work closely with health and care partnerships and Place leads as part of their roles in the newly developed team structure.



Neighbourhood level



Neighbourhoods are smaller areas that make up a Place, with populations between 30,000-50,000 residents. They operate at Primary Care Network level. Primary Care Networks are groups of GP practices which work with other providers and neighbourhood teams to address the health needs in an area.

A great example of how Neighbourhood-driven forums can lead to positive change is the 'hub' run by the community organisation Rainbow Services in Harlow. The hub works in partnership with Mind in West Essex, Harlow Foodbank, Citizens Advice and the Volunteer Centre Harlow. People affected by crisis situations can access a food bank at the hub, as well as information on community and physical activities, access to volunteering and a school uniform service. Staff from the Hub support patients registered with GP practices from the North Harlow Primary Care Network, Citizens Advice staff base themselves in local GP surgeries, and there are regular pop-up sessions throughout the town.

The ICB's communications and engagement team will work to support Neighbourhood-based grass roots activities, such as community events and meetings, in order to hear from local people about their experiences of health and care services, encourage more people onto our forums and groups, and to share information. Examples could include supporting health awareness days run by a GP surgery or community, attending Freshers Fairs and careers events or supporting refugees with settling into the local area.

Neighbourhoods will not be linked directly with the ICB's Patient Engagement Forum. Instead, the work happening in Neighbourhoods will support public engagement with the health service and enable the ICB to reach into communities which might not actively engage with the NHS in more formal settings.

Engagement within Integrated Care Partnerships (ICPs)

Integrated care partnerships are a statutory element of an integrated care system. They are jointly run by the integrated care board - the NHS element - and local authorities.

The Hertfordshire and West Essex ICP is transparent and accountable to our communities, meeting in public with minutes and papers available online.

Healthwatch Hertfordshire and Healthwatch Essex are members of the ICP and bring independent insight, expertise in engagement, and constructive challenge to the partnership.

There is an expectation placed on all ICPs to fully involve people and communities in every system in all aspects of the development of the ICP integrated care strategy. ICPs must say how they have involved, engaged and listened to local people and explain how they have acted in response to these views. Our Hertfordshire and West Essex ICP has adopted the same approach to involvement and engagement as the ICB.

Developing successful Patient Participation Groups (PPGs) and PCN patient groups

PPGs are an invaluable community of patient advocates and GP surgery ambassadors. Many have enjoyed close relationships with the area's three former CCGs. Some have faced difficulties with their development and effectiveness, particularly during the COVID-19 pandemic.

In 2022, the ICB and the representative group the Patient's Association have run a project supporting practices and PPGs to establish, grow, diversify their membership and develop. The work has been led by a steering group of patient voice members from PPGs, GP practice managers, Engagement and Primary Care leads and Healthwatch representatives.

By encouraging grassroots involvement in these very local groups, the ICB can nurture a more representative generation of patient ambassadors.

Meanwhile, some primary care networks are developing ways to get patient representation to cover a whole network, with examples including setting up a kind of PCN PPG, or at the very least having one person representing the group's PPGs at meetings and within network-focused discussions. There are different approaches being taken, and the ICB communications and Primary Care colleagues are supporting on these when requested to do so. The PPG development work complements the evolution of PCN and Neighbourhood-level representation furthermore.

Resourcing and working with patient and public voice volunteers

Communications and engagement professionals from the ICB and ICP member organisations will support the new involvement and engagement framework, with most of the joint activity at Neighbourhood and Place and Health and Care Partnership level. Some partnership working of this sort happens already, but this is an area of development for our system. By working together on a range of projects as System, Place and Neighbourhood level, involvement and engagement activity can be more effectively coordinated.

ICB communications and engagement leads will oversee the System-level work, meaning they have oversight of the Patient Engagement Forum, and work with Patient Experience and Governance leads.

The ICB's communications and engagement team has restructured with more emphasis on engagement work, which will help ensure that involvement and engagement principles continue to be embedded through workstreams and projects.

Learning from people and communities who don't usually get involved in decision making

Increasing the number of different people who are able, or willing, to be engaged in health and care matters which are important to them is an ongoing challenge.

Those representing patients, carers and communities are often white, literate people with access to the internet, people who have more free time to engage and be involved, people who can drive to meetings or join them online, or people who have a professional background in health and care.

Young people, people with caring responsibilities, people experiencing poverty, those not online, people facing language and communication barriers, refugees seeking asylum and people with physical and learning disabilities are just some groups whose views are under-



represented.

The ICB needs to offer options to actively involve and engage them, and be flexible to their needs. It can do this by committing to:

- offering online forums that mirror a group who meet in person and / or arranging more than one meeting about the same topic to increase opportunities for participation.
- tapping into existing networks, such as established community listening events, social groups, or forums run by member organisations of our Integrated Care Partnership, such as community policing priority forums or district council engagement events
- running events at places where there is a bus route, free or cheap parking, hearing loop equipment and so on
- running events at places where people go (e.g. a place of faith, a health and wellness hub, day centre etc.)

Stakeholder groups connected to the system represent different communities, which is evident at Neighbourhood level (with some communities described in more detail in Appendix 3).

Training and development

Equipping people and communities

Taking part in regular involvement and engagement as a patient or service user will require ongoing development so they feel confident to execute their role effectively. To support this, we will:

- provide opportunities for peer-to-peer support between those with experience in involvement and engagement and those who are newer to it
- provide and share training and development opportunities and tools e.g. webinars, workshop days, and courses.

We will also:

- ensure we're meeting the needs of individuals and follow up any challenges for them when they are involved in a piece of work (for example, we will ask people if they have sensory and accessibility needs, what pronouns people use, whether we need access to mental health first aiders, safeguarding etc.)
- reimburse out-of-pocket costs in line with policies
- regularly thank people for their time and commitment through celebration events, formal letters, and putting them forward for award schemes to help highlight their contribution.

Equipping people working in the system

Making engagement relevant, real and meaningful is very important - the ICB needs to be resident-focused, initiating conversations on topics that are important to people and communities and that they will want to join in.

People and communities often appreciate the opportunity to hear directly from experts in



their field, such as clinical leads and so that means involvement and engagement activities involve a range of colleagues. We will support other colleagues to help deliver presentations, take part in events, and proactively look for engagement opportunities.

The toolkit for involvement and engagement

There are tried and test involvement and engagement tools which the ICB and ICS already uses widely. We will also use digital and non-digital feedback mechanisms, and ensure we ask people what tools and methods suit their needs.

When designing services and to ensure we 'start with people' to start the engagement process, there needs to be co-production approach wherever possible. Co-production gives the opportunity for people to come together with staff at organisations and commissioners to work in an equal way to design, deliver and monitor services and projects.

There are co-production boards at local authority level, such as the Hertfordshire All Age Autism Co-Production Board and examples of services developed through co-production at place include the Essex Local Offer for families and children with special educational needs and disabilities. Similarly West Herts Hospital Trust has implemented a robust approach to co-production and the South and West Hertfordshire Health and Care Partnership has committed to a co-production approach.

To build on the culture of co-production already in parts our system, and to nurture, share and spread this way of working, we will explore co-production training for all colleagues and people and communities who have not done it before.

Examples of feedback tools:

- Surveys conducted by the ICB and our wider partner organisations, such as Healthwatch and county and district councils
- Health Matters webinars to help get more people interested in health and care topics, learn, and give feedback
- Reader Panel (to review and help develop engagement and communications to ensure they are accessible and inclusive)
- Focus groups
- Events bringing together a range of people
- Informal drop-ins into existing services
- Online 'listening in' to conversations already happening in local areas, such as neighbourhood-specific social media groups
- Online for a such as patient experience groups on Facebook and user reviews on google and trip advisor
- Feedback from annual patient surveys, PALS teams in provider organisations and from the ICB's own patient quality team.

Social media and digital networking will be two fundamental tools. Setting up carefully administered private and open forums on channels such as Facebook can help draw in engagement in different ways – for instance, a Cancel Out Cancer Facebook group helps participants of the campaign sessions keep in touch and share news they find about cancer.

Using insight and data



The system should use insight from trusted sources to help create a bank so we can what the data is telling us about people and communities using health and care services, with the stories and feedback from those people.

This will rely heavily on regular input from Population Health Management and Public Health data, data held by councils from the engagement they have, national and local survey results, Office of National Statistics data and reports, and more.

A data and insight bank should not duplicate anything already in place but act as one data and insight bank for Hertfordshire and West Essex to inform the activity for involvement and engagement.

The ICB also benefits from roles such as social prescribers, link workers, community champions, carers leads and Macmillan nurses who connect with PCNs. They are gathering data and insight about how people are accessing services.

Next steps

Some of these steps are already happening (such as PCN engagement support), and some will need to take place concurrently with others (such as determining roles and remits of public and patient members at System level and the groups they will be in):

- Establish Key Performance Indicators and an evaluation framework, supported by the Task and Finish group
- Determine the role and remit of the Patient Engagement Forum, with Terms of Reference, and engage exec and non-exec lead for this Forum
- Determine the role and remit of other groups at the System level
- Write a 'how to' for decision makers for service change process (including a Patient and Public Involvement Assessment and Planning Form). Examples from Joined Up Care Derbyshire <https://joinedupcarederbyshire.co.uk/involving-people-communities/guide-to-working-with-people-communities/>
- Work with Place and HCP directors to explore the scope of HCP-led public forums and joint principles
- Connect with PCNs to develop their PPG representation per network (ongoing PPG development at practice level)
- Launch the Forum and establish connection / role with potentially new patient voice partners by in early 2023 (e.g. those linked into HCP, experts by experience)
- Establish a mechanism for gathering insight within the system from different sources including scoping the resource needed to analyse, interpret, and present insight which informs decision making
- Set up a social media-based involvement network for anyone registered with a GP to join
- Continue to advertise the regular e-newsletter to stakeholders
- Formalise an Engagement Network within the ICS, for colleagues who run patient and carer experience forums (e.g. PALs team coordinators, provider trust public engagement and experience colleagues, etc.).

Appendix 1 Our legal duties

National Health Service Act 2006



Under section 14Z59 of the Act, NHS England assesses the performance of ICBs on various duties, including those under section 14Z45 for public involvement.

This will be included in the new System Oversight Framework, building on the approach that happened for CCGs. The ICB will need to provide evidence that it meets the 10 principles in this guidance of Working with People and Communities and the difference it has made. It will look for evidence of meaningful involvement taking place consistently across the ICB's places and neighbourhoods.

Our involvement of local people and communities should be an ongoing approach that ensures we provide opportunities for people to raise the issues and ideas that matter to them and make decisions with them about their health and care services.

There are also specific legal duties for commissioners and providers of health and care services. Our approach will ensure we meet these.

This sets out the main duties on NHS bodies to make arrangements to involve the public under sections 13Q and 14Z44 (for NHS England and Integrated Care Boards) and section 242 (for NHS trusts and NHS foundation trusts).

Health and Care Act 2022

This makes it a legal requirement for community involvement to include the involvement of carers and representatives (if any), as well as patients and services users themselves.

The Gunning Principles

These four principles relate to formal public consultation and guide what constitutes a fair consultation exercise.

The triple aim duty

NHS England, integrated care boards, and trusts are subject to the new 'triple aim' duty in Health and Care Act 2022 (sections 13NA, 14Z43, 26A and 63A). This requires us to have regard to the 'triple aim' of better health and wellbeing for everyone, better quality of health services for all individuals, and sustainable use of NHS resources.

The Equality Act 2010

This prohibits unlawful discrimination in the provision of services on the grounds of protected characteristics – age; disability; gender reassignment; marriage and civil partnership; pregnancy and maternity; race; religion or belief; sex and sexual orientation.

The Act requires public sector organisations to eliminate unlawful discrimination, harassment and victimisation and other conduct prohibited by the Act, advance equality of opportunity between people who share a protected characteristic and those who do not, and foster good relations between people who share a protected characteristic and those who do not.

In line with the requirements of the Equality Act 2010, the ICB is required to:

- evidence the analysis that has been undertaken to establish whether our policies and practices have (or would) further the aims of the general equality duty
- provide information that we have considered when carrying out an analysis
- provide details of engagement (consultation / involvement) with people whom we consider would have an interest in furthering the aims of the general equality duty.

To meet the requirements of this duty, the ICB will carry out an Equality Impact Assessment process at the primary stages of planning changes, such as:

- organisational change



- considering any new or changing activity
- developing or changing service delivery
- procuring services
- developing projects
- developing a policy / procedure / guidance or changing or updating existing ones.

The Equality Impact Assessment process will be used to assess whether there may be any barriers or difficulties, harassment or exclusion as a result of a planned change, or in fact any positive impact such as the promotion of equality of opportunity, developing good community relationships, encouraging participation and involvement as experienced by service users, patients, carers, relatives, staff, the general public and key stakeholders.

Health inequalities

NHS England and Integrated Care Boards are also under a separate statutory duty to have regard to the need to reduce health inequalities of access to health services and the outcomes achieved (sections 13G and 14T of the NHS Act 2006).

Public Services (Social Value) Act 2012

There are several benefits to local communities in embedding social value in commissioning, including improved service delivery, health creation and an increase in the resilience of communities. This Act requires commissioners to think about how they secure wider social, economic and environmental benefits.

Appendix 2

Draft ICB Working with People and Communities (May 2022 submission)

<https://hertsandwestessex.icb.nhs.uk/downloads/file/4/working-in-partnership-with-people-and-communities-pending-approval-by-nhs-england-and-nhs-improvement->

NHS England Working with People and Communities Guidance (updated July 2022)

<https://www.england.nhs.uk/publication/working-in-partnership-with-people-and-communities-statutory-guidance/>

Appendix 3 Terminology

The term 'involvement and engagement' describes the different ways we connect people and communities.

Engagement is ongoing participation and working together on a regular basis. It helps relationships flourish, helps people have an awareness of what is happening with health and care, and means we are always open to feedback.

Involvement is short- to medium-term participation that might look at service changes or design. It might only need to involve one or two communities or patient cohorts such as parents and maternity, those with long term conditions, or a GP practice's registered patient base.

'Community' is everyone of all ages, their representatives, relatives, and unpaid carers whether or not they access health and care services and support. 'Communities' are groups or networks of people not just in the geographical sense, but also by how they identify or share interests.



'Hard to reach' is an out-moded term for people and communities being hard to reach, Instead, because someone in a marginalised or challenged position might find our system difficult to navigate and engage with, it us in fact which are 'hard to reach'. Some communities have a distrust of working with health and care professionals and it can take time to build up that trust, but it is not impossible to find the opinions and feedback.

Therefore, the ICB and ICS should use 'seldom heard', 'underrepresented', or 'facing health inequalities' which is more accurate.

'Inclusivity' describes having the Equalities Act 2010 protected characteristics always at the forefront of planning involvement and engagement activity, as well as considering carers, those in poverty, and those who are digital excluded, so they are not overlooked. 'Inclusion health groups' is also a term used to described those who experience the worst health inequalities either because they're at risk of, or living within extremely poor health caused by poverty, marginalisation, multi-morbidity and social exclusion.

A person's experience can be further impacted on by discrimination and stigmatisation, and not being accounted for in electronic records (such as healthcare databases). These can overlap with protected characteristic groups.

These are any socially excluded population including, but not limited to:

- Gypsies, Roma, Travellers, Showmen and Liveaboard Boaters
- people experiencing homelessness
- people experiencing alcohol and/or drug dependence
- sex workers
- vulnerable migrants and refugees
- young carers
- victims of modern slavery .
- people in contact with the criminal justice system.

There are other groups that experience barriers to accessing services, like people with a learning disability and autistic people, and people with severe mental illness. They can also belong to inclusion health groups.

Appendix 4

The task and finish group involved in the development of involvement and engagement activity are patient voice volunteers in the local health and care systems. The group members, as well as supporting the delivery of the ambitions in this document, are keen to also focus on:

- what good looks like
- a self-assessment tool to review progress of patient engagement
- how we can develop KPIs.

Current patient voice volunteers have built up a network of people and flow of information and knowledge. This can be built on as the system working matures and to help them explore this further, patient voice champion Alan Bellinger has devised a 'Maturity Model'. It highlights aspects such as:

- the effectiveness of a network which facilitates the flow of information and knowledge
- the origin and scope of the content that flows through the network (such as different health and care topics covered through hosting webinars)



- the extent to which patient voice volunteers are engaged within the governance part of involvement and engagement.

This table shows how factors such as networking and running awareness events with a structure 'content' approach evolves and matures over time:

HWE Patient Engagement Maturity Model

