Health and Social Care Partnership
Strategic Clinical Networks

Patients, Carers and Public (PCP) Engagement and Participation Strategy

September 2018

Content

Background

The Greater Manchester Health and Social Care Partnership (HSCP) Strategic Clinical Networks (SCN) are committed to meaningful engagement with patients, carers and members of the public. This strategy provides a direction on how the strategic clinical networks proactively engage patients with lived experience, carers and members of public (PCP).

Our engagement and participation strategy contributes towards a new relationship between public services and residents, communities and businesses that enables shared decision making, democratic accountability and voice, genuine co-production and joint delivery of services (Greater Manchester Commissioning Strategy: 2016).

This strategy is part of our Health and Social Care Partnership Engagement Framework which builds on years of partnership working in Greater Manchester, involving both fully established and more recently formed groups and networks following devolution in 2016.

The Health and Social Care vision is that we become a place where we take charge and responsibility to look after ourselves and each other. There's a role for everyone, from the individual to the family, carers, the community, the voluntary sector and the public bodies to work together

The health outcomes for GM people are worse than those in other parts of the country and health inequalities are deep-rooted. For example:

- Older women in Manchester have the worst life expectancy in England.

- The high prevalence of long term conditions such as cardiovascular and respiratory disease mean that GM people not only have a shorter life expectancy, but can expect to experience poor health at a younger age than in other parts of the country

- Our population has aged and our older population will increase by 25 per cent by 2025

- Supporting and engaging Children and Young People and Adults using our mental health services: where one in four have mental health.

- End of life Care is important to all, on average 47% of people die in an Acute Hospital when a large proportion of peoples preferences are to die at home

- As more people have developed multiple long term conditions the focus has shifted from curing illnesses to helping individuals live with chronic ill health such as cardiovascular disease (CVD), diabetes, respiratory disease and clinical frailty.

- 31.73% of people registered with GP practices in GM aged 65 and over have had a clinical frailty assessment in primary care using the appropriate tool. 9.8% of patients assessed as having moderate/severe clinical frailty have had a fall. Only 2.92% of patients assessed as having moderate/severe clinical frailty were referred to a falls clinic.

- Diabetes causes over 1,000 premature deaths in GM each year. Compared to the general population, people with diabetes have a 55% higher chance of having a myocardial infarction; a 34% increased risk of having a stroke; a 164% increased risk of having renal replacement therapy; a 221% increased risk of having major amputation above the ankle and a 337% increased risk of having a minor amputation.

- CVD causes a greater burden of morbidity and mortality in GM than in England. Manchester City Council has the highest CVD mortality in England with 94.9 deaths per 100,000 as compared to an England rate of 46.7 deaths per 100,00. It is a preventable disease, driven by poor diet, tobacco, alcohol, physical inactivity, and pollution, all greatly exacerbated by socioeconomic inequalities.

- *Around 191,000 people have diagnosed asthma in GM (6.4%). A further 69,000 have diagnosed Chronic Obstructive Pulmonary Disease (2.3%). Emergency admissions for both diseases are amongst the highest in the country.*

- Compared to the England average, 32,000 more children in Greater Manchester grow up in poverty and boys in Greater Manchester have a life expectancy 1.7 years less than the England average. In the average reception class in Greater Manchester 1 child more does not achieve the good level of development (or school readiness) compared to the England average.

In order to improve the health outcomes, HSCP has established the following strategic clinical networks.

- Long term Conditions Networks (Diabetes, CVD, Respiratory and Frailty)
- Children and Young People Network
- Mental Health Network
- End of Life and Palliative care Network

What do we mean by patient, carer and public engagement and participation?

There are many different terms used to describe ways in which patients, carers, service users and members of the public can get involved and shape healthcare – involvement, engagement and participation being just some of them. For the

purposes of this strategy, we are using the term 'engagement and participation' to include all of the activities described in 'The Ladder of Engagement and Participation'. We do not see this as being hierarchical, but where all strands of the ladder have equal value if used appropriately and meaningfully undertaken. See Diagram below:
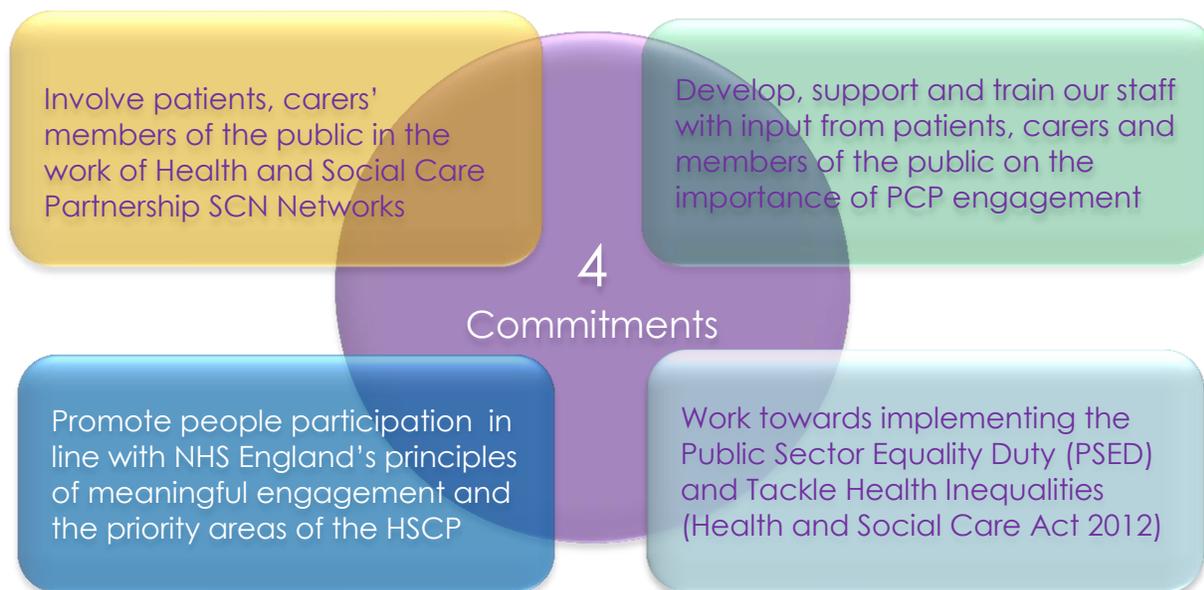
The "Ladder of Engagement and Participation" (based on the work of Sherry Arnstein)				
Informing	Consulting	Involving	Collaborating	Devolving
Provide PCP with balanced and objective information to assist them in understanding problems, alternatives, opportunities and solutions. For example, websites, newsletters, emails and press releases.	Obtaining PCP feedback and analysis, alternatives and/or decisions. For example: surveys, citizen panel and focus groups.	Working directly with PCP to ensure concerns and aspirations are consistently understood and considered. Examples include: PCP Engagement Networks and Chairs of PCP network Group	Working in partnership with PCP in all aspects of the decision making process, including the development of alternatives and preferred solutions. Examples include: development of pathways, standards and guidance.	Placing decision in the hands of patients, carers and members of the public (PCP). For example engaging and asking PCP to deliver some of the programme and project in partnership with our partners

Our vision for patients, carers and public engagement

Our vision is to ensure that the HSCP SCN Networks projects, programmes of work and priorities are influenced by patients with lived experiences, carers and members of public.

Our commitments to engagement

In order to achieve our vision, we have adopted four key commitments for engagement across the Health and Social Care Partnership. These are outlined in the following diagram.

Involve patients, carers' members of the public in the work of Health and Social Care Partnership SCN Networks

Develop, support and train our staff with input from patients, carers and members of the public on the importance of PCP engagement

4
Commitments

Promote people participation in line with NHS England's principles of meaningful engagement and the priority areas of the HSCP

Work towards implementing the Public Sector Equality Duty (PSED) and Tackle Health Inequalities (Health and Social Care Act 2012)

Appendix "B" shows action plan on how we will deliver these commitments and how we will know when we have achieved them.

Principles of engagement

NHS England has developed some principles of engagement[1] based on a review of research, best practice reports and other evidence. We are committed to applying these principles in the engagement that we undertake.

Working with each other

- Our relationships will be conducted with equality and respect.
- We will listen and truly hear what is being said, proactively seeking participation from communities who experience the greatest health inequalities and poorest health outcomes.
- We will use all the strengths and talents that people bring to the table.
- We will respect and encourage different beliefs and opinions.
- We will recognise record and reward people's contributions.
- We will use plain language, and will openly share information

Working well together

- We will understand what's worked in the past, and consider how to apply it to the present and future.
- We will have a shared goal and take joint responsibility for our work.
- We will take time to plan well.
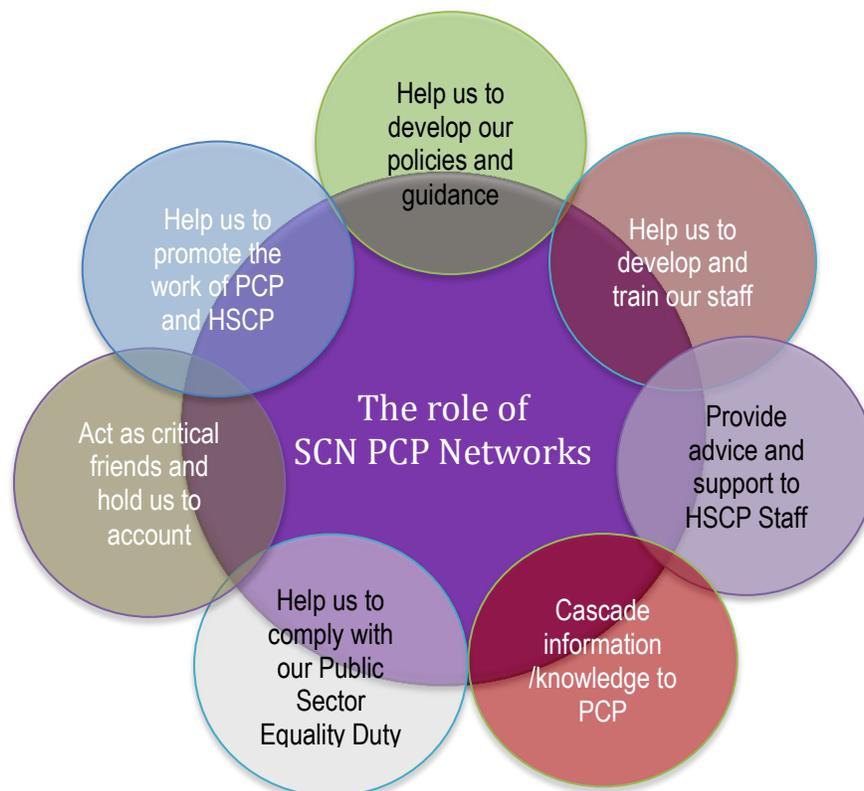- We will start involving people as early as possible.

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[1] Transforming Participation in Health and Care, NHS England, September 2013
http://bit.ly/1b4JVOo

- We will give feedback on the results of involvement.
- We will provide support, training and the right kind of leadership so that we can work, learn and improve together. Engagement activity should include working with:
  ➢ Communities that experience difficulties accessing health, third sector or social services, or have health problems that are impacted on by their social circumstances;
  ➢ Communities and groups with distinct health and social care needs;
  ➢ Communities and groups who experience poor health/social outcomes;
  ➢ People who have characteristics that are protected under the Equality Act.

Health and Social Care Partnership Strategic Clinical Network approach to engagement: making it happen

We will employ a range of methods to involve patients, carers and the public, to seek the range of views of the local population. We will provide opportunities for patients, carers and the public to get involved at all levels of our work. This approach allows people to be involved as much or as little as they choose. Fundamental to this approach is maintaining a PCP Network database of interested PCP who are interested in being involved at different stages of the ladder of participation. We have adopted the following approaches to ensure that people participation is embedded across all of our work.

1. **SCN PCP Network:** A PCP Network will be developed as a platform for participation and a means of connecting with people about involvement opportunities. The PCP Network will consist of interested individuals who are involved in the SCN Networks and those that are interested in the work of the Clinical Networks. The PCP Network database will be advertised to prospective members through existing contacts and stakeholders, as well as third sector organisations across our footprint.

The role of SCN PCP Networks

- Help us to develop our policies and guidance
- Help us to develop and train our staff
- Provide advice and support to HSCP Staff
- Cascade information/knowledge to PCP
- Help us to comply with our Public Sector Equality Duty
- Act as critical friends and hold us to account
- Help us to promote the work of PCP and HSCP

The short term plans

Each SCN network will engage with PCP members on their programme and priorities. Examples of current and short term plans are outlined below:

a) **Mental Health Network** will develop engagement groups/networks to ensure that the voices of services users are heard and that the PCP and Children and Young People have the opportunity to be involved in the mental health network priorities and programmes. We will do this by:

- **Adult Mental health:** supporting the establishment of the HSCP Adult Mental health Service User Network. The network will provide an opportunity for the SCN adult mental health clinical leads, programme leads and project managers to update, co-design, share good practice and continuous engagement on programmes with service users on a regular basis.

- **Perinatal Mental Health**. Perinatal Mental Health network will ensure that families with lived experience of perinatal mental health are engaged in the work programme. Through representation and involvement in all working groups, dedicated PCP meetings/engagement as well as a virtual platform for two way sharing of information to shape future services while always having the baby in mind.

- **Children and Young People's Mental Health** ensuring the priorities and experiences of children and young people, and their families are visible in all of CYP Emotional wellbeing programme. This includes but not limited to service users and families be represented at the CYP Board meetings and all project steering groups. Funding has been allocated to support this to happening in a meaningful way across the programme.

  A CYP User Voice will be set up in order to empower young people. parents and carers by working collaboratively with several VCSE organisations(Young Minds, 42nd Street, Youth Support and Young Health Matters) to commission young people from their respective organisations to form a Young Person's Mental Health User Reference Group. The User voice group has already assisted with the development and delivery of the crisis care pathway workshops. Additionally service users will be involved in the evaluation of projects.

b) **Long term Conditions (Diabetes, CVD, respiratory) Network** will continue to engage with PCP in the development of GM initiatives to ensure all initiatives contribute to improved health and experience of care. PCP membership on key steering groups and consultation through specific PCP groups and events will guarantee that service users will not only have the opportunity to input in quality improvement projects, but also to ratify them.

c) **Dementia United** is committed to ensuring engagement and involvement from people living with dementia and their carers. This will be done by ensuring representatives throughout the structures, both at strategic level and through localities specific key focus areas. Engagement with organisations such as Health watch also adds real value to the work of Dementia United.

d) **Children and Young People** will ensure that representatives of young people and their parents and carers are members of the children's programme board. We are employing a networked approach to engagement getting the voice of service users and spreading our messages via established service user groups representing all children and families and specific groups such as children with special educational needs and disability (SEND).

e) **Maternity** will ensure representatives of service users are members of all of the maternity programme boards. We will utilise a networked approach to engagement collaborating with representatives of multiple service user groups. Where possible elements of the programmes will be devolved to existing service user groups, in particular the GMEC Maternity Voices Partnership,

f) **Palliative and End of Life Care** will work to strengthen current engagement and involvement to the work programme, and actively seek additional representation to the Programme Board, and subsequent key areas of work, emphasising the significance of localities taking this approach. Partnerships with the VCSE are also being pursued to add the citizen's voice to the conversation.

The medium to long term plans

Moving forward it is envisaged our programmes will adopt a more systematic and consistent approach to working with PCP and 3rd sector organisations.

Currently over 90% of SCN work streams have a 3rd sector organisation with members and support that could contribute to the development of future proposals. Well established organisations such as the British Heart Foundation, the British Lung Foundation and Diabetes UK are instantly recognisable and provide gravitas to people with associated conditions. These organisations already have their own local PCP cohorts and groups and a much wider PCP community which would aid us in the difficult task of finding new PCP (instead of using the ones we already know and always use in the system).

There are other benefits too. Often, such organisations provide train individuals to be representatives preparing them should they wish to represent wider PCP views on task and finish groups or Boards. PCP would feel they have an active

role in shaping local proposals. We would have consistent affiliations with the 3rd sector and stronger links with their own initiatives; there would be opportunities to bring PCP all together in in multi-morbidity events and workshops, and PCP members would continue to feel supported by their charity following the completion of our work streams.

Outline structure

Each work stream or programme would have a PCP group to which all emerging proposals from the SCN are run by and through the 3rd sector we could agree which PCP members are most appropriate to appear on other working groups (see example structure below).

Example structure of how PCP can be used
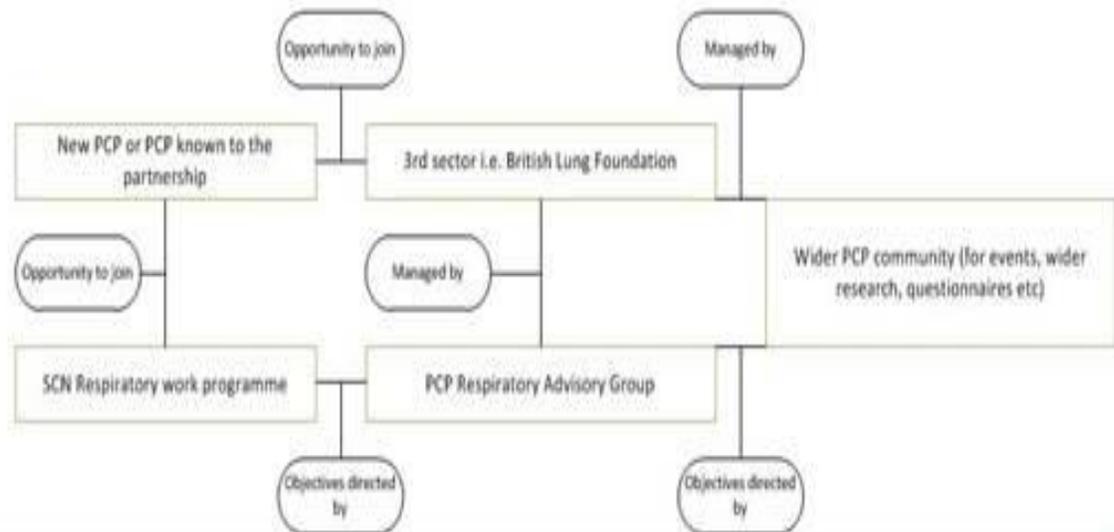
The groups could be logistically managed by the 3rd sector organisation or the SCN (whichever is deemed most appropriate). Groups in some cases may be virtual, and for wider views, questionnaire may be sort.

In addition, all or multiple groups could be brought together as appropriate to formulate a wider PCP network. This might be to discuss proposals to improve care for people with multi-morbidity. Individual organisations could use this opportunity to talk about what their own plans and initiatives are. It will also provide PCP the opportunity to become members of other 3rd sector organisations (see example of system below).

Example of system wide use of PCP
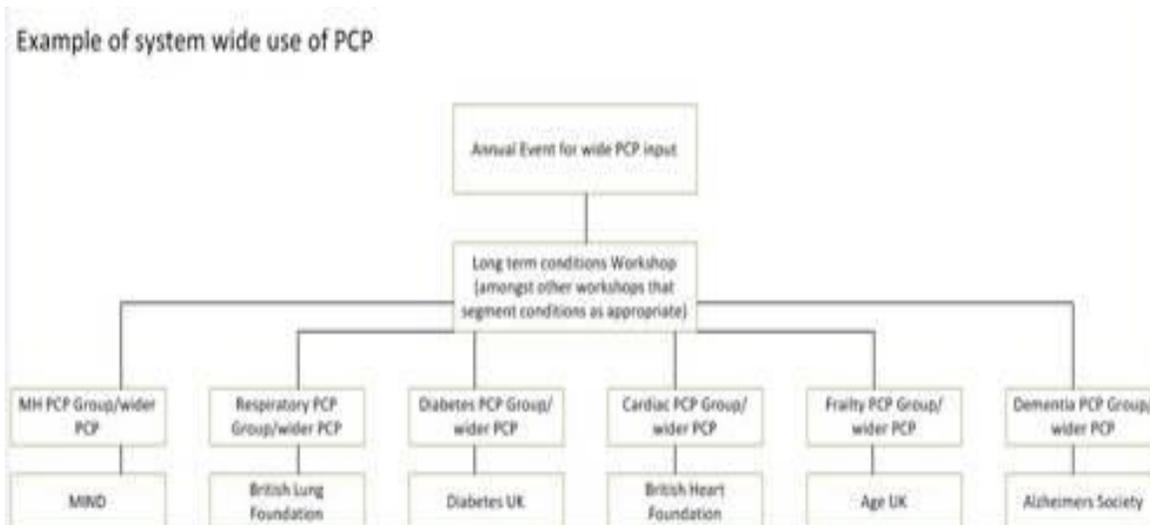
2. Health and Social Care Partnership PCP Engagement Staff Champions

Each SCN Network will nominate one/two PCP champions to support and implement this strategy. The main role of the PCP Staff Champion will be to act as leaders who will promote and advance PCP within their networks work areas/domains. It is the responsibility of all HSCP SCN staff to ensure that PCPE is meaningfully embedded within their work. The PCP Network Staff Champion will act as a supportive resource to their colleagues within their own teams. PCP Staff Champion will:

- Be committed to promoting PCP, including the involvement of seldom heard groups and supporting the adherence to the Equality Act 2010 and the NHS constitution

- Attend PCP, Equality and Reducing Health Inequalities training sessions and help the PCP group to organise seminars, master classes, conferences and training sessions when / if required

- Take responsibility to update themselves on PCP, equality and reducing health inequalities issues affecting patients, carers and members of the public

- Cascade information and knowledge gained by education and training to members of their team

- Feedback to the PCP Advisory Group any issues that may arise from team members and that may improve PCP

- Treat others with dignity and respect and promote the vision, values and behaviours, including the equality and fairness commitments of NHS England

- Work as a PCP Champions team to develop and organise events, development days and contribute towards developing PCP guidelines

3: Learning the lessons and sharing good practice group

We are committed to learning from "what has worked and what can be improved" and we will do this by bridging the chairs of the PCP networks together on a regular basis. This will provide an opportunity to share good practice as well as learning from other network meetings.

Our commitment to ongoing supporting PCP members and staff

We are committed to working with our PCP champions, PCP networks and advisory groups to provide ongoing support, training and development for our PCP Engagement Champions, staff, and PCP members so that they are kept up to date and have relevant information to make informed and meaningful decisions.

Our partners

We will work in partnership with a wide range of other groups and structures for success. Opportunities for joint working on engagement will be actively sought. Key partners will include:

- Local Accountable Care Organisations/ Integrated Care Providers
- Clinical Commissioning Groups (CCGs)
- The Mayor Office
- NHS England Regional and National Office
- Public Health England
- Voluntary and Third sector – in particular the range of charities and voluntary organisations serving protected characteristics and seldom heard groups.
- Local Health-watch organisations
- NHS Quality Improvement

We are committed to working in a transparent manner and plan to keep our partners up-to-date with the work of the HSCP SCN PCP by:

- Publishing work plans and contribution to annual reports
- Input into regular stakeholder briefings
- Contribution to and taking part in stakeholder events when possible
- Publishing outputs and outcomes from projects and programmes highlighting the PCP engagement.

Review of patient insight

As a learning Health and Social Care Partnership SCN we will learn from people's experiences of NHS services. We will regularly review and use patient insight to

develop our PCP engagement work. There is a multitude of sources of patient feedback already in existence that can be used for this purpose: for example national inpatient survey, national outpatient survey, national cancer patient survey, friends and family test and complaints, in addition to our own sounding board and directorate PCP members experience we will also:

- regularly review patient experience of relevant services at meetings – through the Insight Dashboard – insight used to direct work programme
- Review and use of patient insight core component of all work projects
- Commissioning research into people's experiences of a specific service where this does not already exist

Resources

Reimbursement of people involved

We recognise that patients, carers and members of the public's time are valuable and should be appreciated. Our aim is to ensure that PCP members are not financially out of pocket when they support our work. We have adopted the NHS England "Working with our Patient and Public Voice Partners" policy (add link) for Reimbursement for all patients, carers and members of the public involved in the HSCP SCN work, meetings, workshops and seminars including training and development days/sessions. The Policy has three Categories of financial support for PCP as summarised below:

1. **CATEGORY A**: open access public meetings/events - no financial support

2. **CATEGORY B**: - Patient and Public Voice (PVV) partners work with NHS England to inform our programmes and policies - out of pocket expenses are provided

3. **CATEGORY C** - "PPV Expert Adviser role" - involvement payments are made

Support for people involved

We are committed to supporting PCP members involved in the work of the HSCP to make it easy for them to participate and so that they have a rewarding experience of working with us and our staff. We will ensure this happens by:

- Providing clear role descriptions and defining activities

- Providing induction to people who get involved, as necessary

- Allocating a key point of contact for people who get involved and responding promptly to any questions or requests

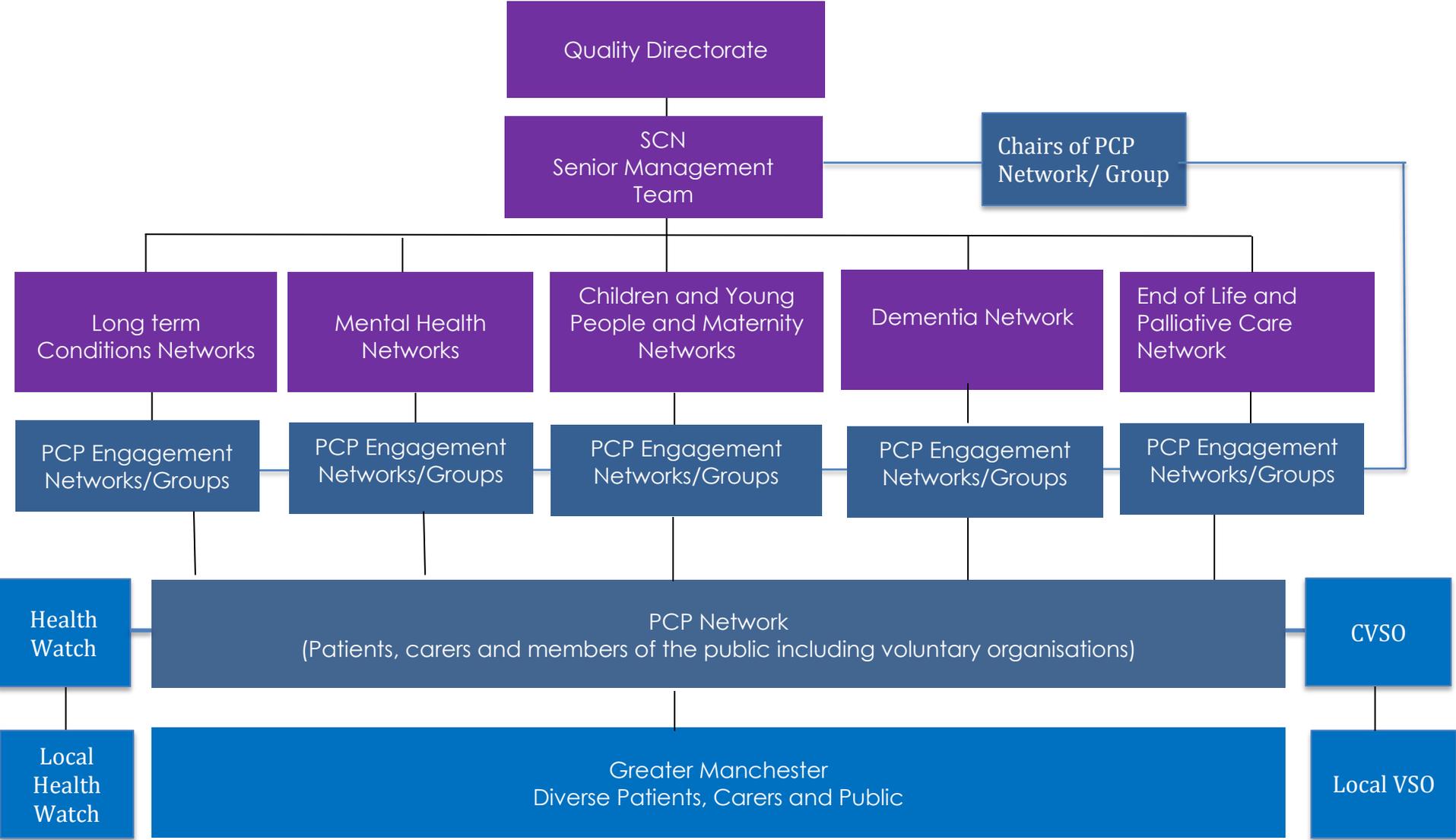- Providing training, as necessary

We acknowledge that it is important to make sure HSCP SCN staff including senior managers and professionals working with HSCP understand the role of PCP members. Part of this work will be developed though the PCP and Staff Development Days.

Evaluation and Review

It is important that we continually evaluate whether the engagement work we undertake is effective and adjust our approach accordingly. We will use the following measures to evaluate our success:

- Positive feedback from the people who have been engaged – that they feel they have been supported and have made a difference

- Demonstrable evidence that the work of the HSCP has been influenced as a result of engagement

- Review of the diversity of the people who have been involved, - have we successfully engaged with particular communities where we know there are health inequalities in the topics we have looked at?, and taking action when appropriate to supporting the adherence to the Equality Act 2010 and the NHS constitution

- This strategy will be reviewed in 12 months' time (August 2019)

Appendix "A" Governance Structure

Appendix "B" Our commitments

What we will do:	How we will do it:	How will we know we have done it?	When will this be done
1. Meaningfully involve PCP in everything we do	1. Establish a HSCP SCN PCP Networks and Groups	• Network and Group established • Audit of strategy	Oct 2018
2. Develop, support and train our patients, public, staff on PCP Engagement	1. Include, identify and use PCP Engagement champions 2. Embed PCPE into our staff Induction sessions 3. Organise training and development sessions, linking in with the charitable sector, for staff and clinicians. Involve patients and members of the public in the training sessions	• PCPE champions identified • Induction policy demonstrates PCP • Training delivered to all staff	Dec 2018
3. Promote PCPE and NHS England's commitments on meaningful engagement in the priority areas of the SCN Networks	1. Involve patients and public in our events and meetings, including the development of our work plan and priorities 2. Ensure collective patient and public involvement is embedded in service improvement and redesign 3. Promote our work with the help of national, regional and local media channels 4. Develop and support the SCN and Senate PCPE Champions Network	• Evidence of patient and public involvement in our events and meetings • Evidence of patient and public involvement in service reform • PPE network established	Dec 2018
4. Advance equality and work towards reducing inequalities	1. Take proactive and positive action to target seldom heard patients and members in our work, decision making structures, process and all areas listed above 2. Train our staff on the Public Sector Equality Duty (PSED) and reducing health inequalities	• Staff trained in the Public Sector Equality Duty and reducing health inequalities • Evidence of Public Sector Equality Duty and reducing health inequalities	Feb 2019