Leeds
Health & Care
Partnership

Public Involvement Workshop

End of Life Care

Nov 2022

#TeamLeeds

Recording

We are recording this session so that we can share the discussion with people who are unable to attend the meeting.

It will be available shortly on the Leeds Health and Care Partnership Website

Welcome and Introductions

Gill Pottinger

GP and chair of the End of Life Care Board

Aim and objectives

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Aim

To develop our approach to public involvement in the population board

Objectives

- Introduce population health and the board
- Review and agree the findings of the insight report
- Review and agree the draft outcomes for the board
- Begin planning involvement on the gaps in our knowledge
- Agree how we represent people at the board and provide public assurance

Outcomes of the workshop

By the end of the workshop participants should have had an opportunity to:

- Understand the role of the board
- Discuss the findings of the draft insight report
- Influence the draft insight report
- Discuss gaps in our knowledge
- Suggest other gaps
- Discuss the draft outcomes for end of life
- Explore ways we can provide assurance that people's voices are heard at the board
- Influence our approach to public representation and assurance on the board

Agenda

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1. **Population Health** - What are population health boards and what is their role?
2. **Experience of end of life care** - What do we know about the experiences of people at end of life care and their family? (our insight)
3. **Population outcomes** - How do we want things to be different for people at end of life and their families? (our outcomes)
4. **Public representation and assurance** – What does public representation look like on the board?
5. **Next steps** - What happens next?

Groundrules

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- Stick to the agenda
- Be honest
- Be open to new ideas
- Listen to others
- Respect confidentiality
- Don’t judge
- Enjoy

Population health

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Population health moves away from 'traditional' thinking about commissioning (planning and paying for) and providing services.

It thinks less about organisations and pathways and more about people, or 'populations'.

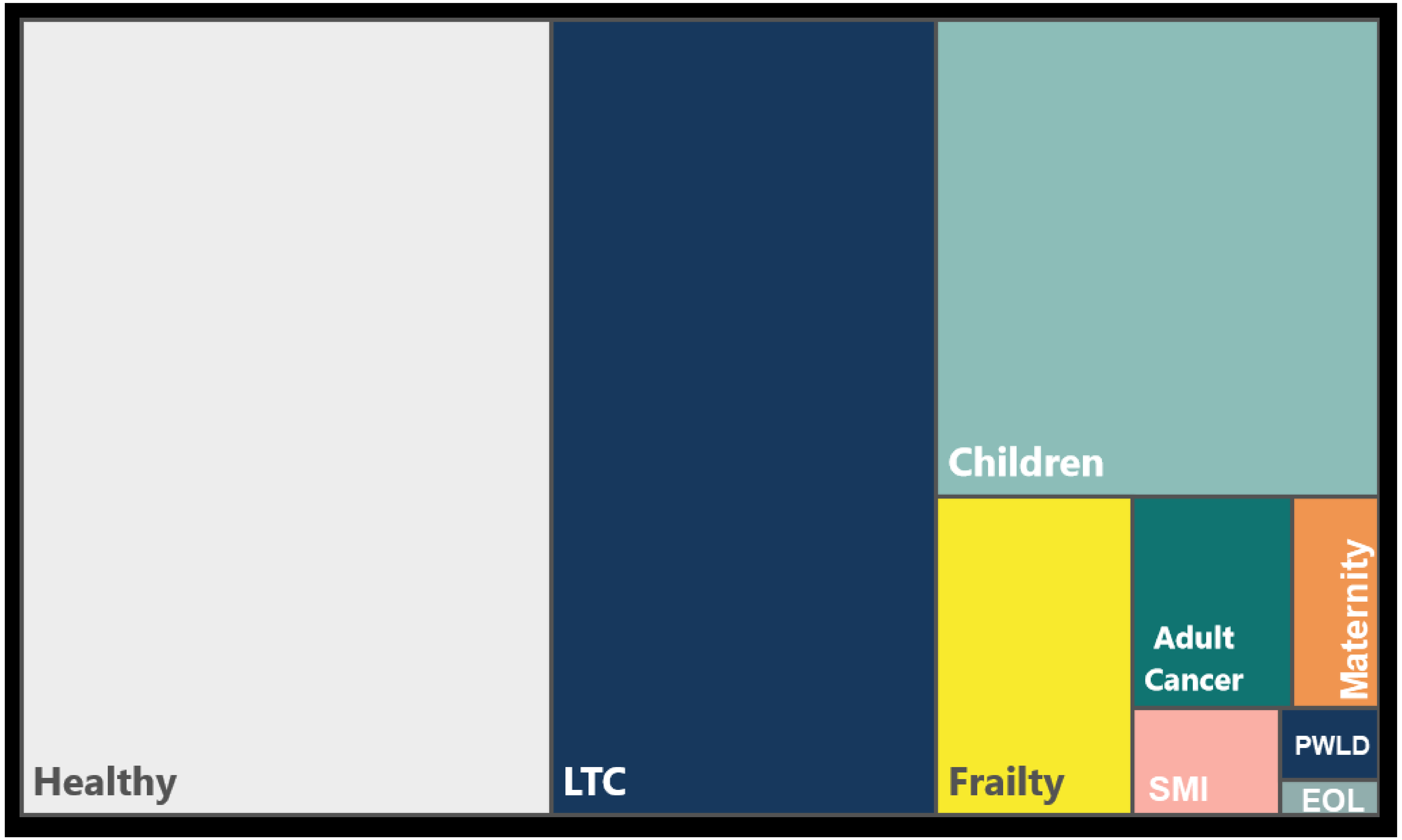
It focuses on:

- The needs of people – what is important to people
- Prevention – helping people stay well
- Outcomes – the difference care makes
- Reducing health inequalities
- Working as partners rather than as organisations (system working)
- The 'wider determinants of health' such as housing and transport

https://www.kingsfund.org.uk/publications/population-health-approach?gclid=EAIaIQobChMI8dWWp_ig-wIVCLbtCh2IKQ7REAAYASAAEgL2w_D_BwE

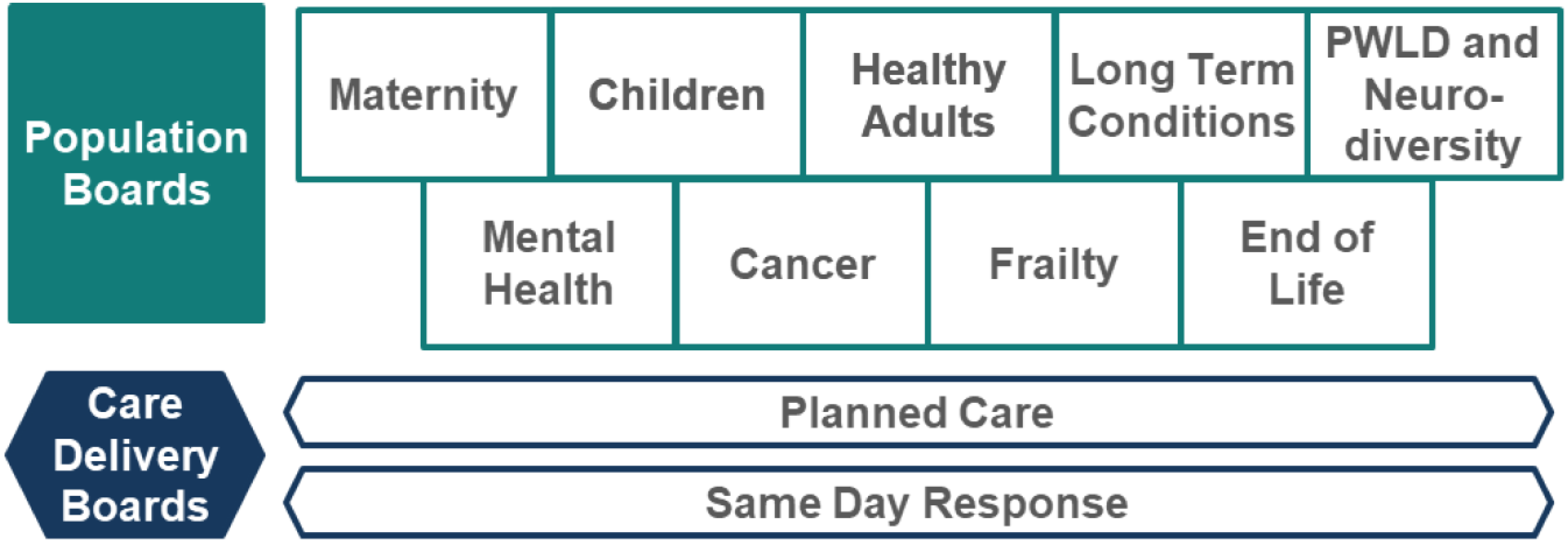
Population health

How the Leeds population would look if we organised by need.



Population health

How we will meet these needs in Leeds?



These boards are responsible for improving (or driving improvements in) the outcomes, experience and value of NHS spend for their respective population…

Working across organisations, across sectors, and focussed on people's needs.

Population health

Boards will be made up of senior representatives from across the health and care partnership.

The boards will be

- **Broad enough** (to represent all partners)
- **Senior enough** (to take critical decisions)
- **Small enough** (to make these decisions)

Population health

The End of Life Population Board

End of life care is defined as care that:

“helps all those with advanced, progressive and incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met through the last phase of life and into bereavement. It includes the management of pain and other symptoms and provision of psychological, social, spiritual and practical support” ***(DH, 2008).***

Palliative care is defined as:

“The active holistic care of patients with advanced progressive illness. It is the management of their pain and other symptoms together with the provision of psychological, social and spiritual support” ***(National Council for Palliative care)***

Population health

What sort of decisions will the boards make?

- Where to allocate funding
- When to make changes to services
- What the priorities are
- How to deliver value (value for money)

It is essential that we involve people in this decision-making process. This workshop builds on our involvement so far and gives us an opportunity to plan future involvement together.

Experience of end of life care

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In Leeds we want to commission (plan and pay for) and provide care that is:

- Safe
- Sustainable
- Patient-centred
- Value for money

We cannot do this without understanding the needs, preferences and experiences of people in our population.

We are committed to 'starting with what we know' about people's experiences and engaging on the gaps in our knowledge.

Experience of end of life care

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Each population board in Leeds is working with partners to review what we already know (an insight review). Our findings will be written into an insight report which will be used by the board to understand the needs of the population and make decisions.

The insight report will:

- Look at what we already know about people's needs, preferences and experiences
- Identify the key themes (the things people often tell us about their care)
- Highlight the gaps in our knowledge (the areas or communities we know least about)

Experience of end of life care

Our insight review for end of life care suggest the following themes:

- People are generally **satisfied** with their experience of using services end of life services and support.
- **Person centred care** is very important to people and the majority of people in Leeds report receiving kind, compassionate care.
- People at end of life and their carers/family/friends value kind and compassionate staff and the majority of people are very happy with the **workforce** in Leeds
- **Information** about services and support for people at end of life is sometimes poor and inconsistent
- Some people tell us that health and care services and support at end of life were often not **joined up**.
- Privacy and dignity is very important to people at end of life and their carers/family/friends **(environment)**
- People at end of life and their carers/family/friends from diverse ethnic communities had views consistent with the wider population. However, they reported having particular difficulties accessing an interpreter **(health inequalities)**
- The health need assessment in 2019 highlights some variation in experience and a need for improvement, especially amongst the following groups, **diverse ethnic communities**, **people from areas of deprivation, men** and **people under 65**.
- There are some potential **gaps** in our insight including feedback from staff and the needs of families and friends of people who die suddenly.

Experience of end of life care

Our insight review for end of life care suggest the following gaps:

- Ethnically diverse communities (in particular people whose first language is not English
- some areas of deprivation,
- men,
- people under 65.
- Feedback from staff working with people at end of life

Additional gaps and considerations identified by stakeholders

- Inequalities in death. (Carers Leeds)
- Needs of carers/families/friends of people who die relatively unexpectedly? (Carers Leeds)
- Practical support needs and preferences of people at the end of life, particularly if they want to die at home? (Carers Leeds)
- How we talk about death and dying as a community, compassionate communities and the practical support that people need when they wish to die at home (Local Care Partnerships Development Team)

Experience of end of life care

Groupwork

- Do you agree with the themes and gaps?
- Have we missed any themes or gaps in our insight?
- How do we prioritise and plan involvement work on the gaps?

Population outcomes

Over the last year we have been working with our partners to agree a set of outcomes for end of life care in Leeds. These outcomes explain what we want to achieve to improve the lives of people at end of life and their carers, family and friends.

The outcomes have been developed with service providers and voluntary sector organisations that represent people using end of life services. The outcomes were shaped used patient, carer, family and staff feedback from various surveys and involvement activities.

Population outcomes

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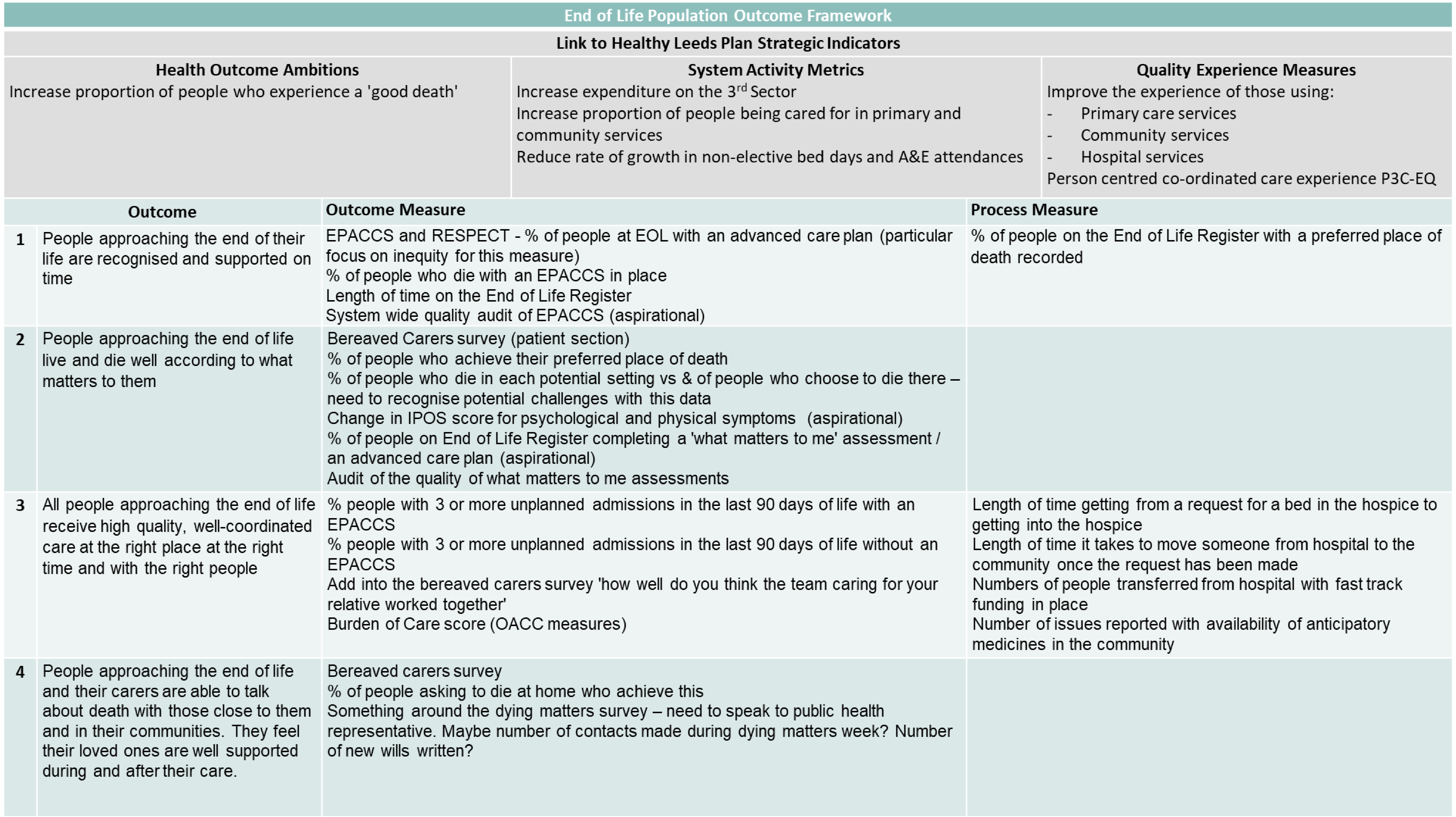
Draft outcomes for end of life care in Leeds

1. People approaching the end of their life are recognised and supported on time
2. People approaching the end of life live and die well according to what matters to them
3. All people approaching the end of life receive high quality, well-coordinated care at the right place at the right time and with the right people
4. People approaching the end of life and their carers are able to talk about death with those close to them and in their communities. They feel their loved ones are well supported during and after their care.

Population outcomes

Each outcome has a set of 'measurables'. These are things we will use to measure whether we have achieved our outcomes.



End of Life Population Outcome Framework

Link to Healthy Leeds Plan Strategic Indicators

Health Outcome Ambitions	**System Activity Metrics**	**Quality Experience Measures**
Increase proportion of people who experience a 'good death'	Increase expenditure on the 3rd Sector Increase proportion of people being cared for in primary and community services Reduce rate of growth in non-elective bed days and A&E attendances	Improve the experience of those using: - Primary care services - Community services - Hospital services Person centred co-ordinated care experience P3C-EQ

	Outcome	**Outcome Measure**	**Process Measure**
1	People approaching the end of their life are recognised and supported on time	EPACCS and RESPECT - % of people at EOL with an advanced care plan (particular focus on inequity for this measure) % of people who die with an EPACCS in place Length of time on the End of Life Register System wide quality audit of EPACCS (aspirational)	% of people on the End of Life Register with a preferred place of death recorded
2	People approaching the end of life live and die well according to what matters to them	Bereaved Carers survey (patient section) % of people who achieve their preferred place of death % of people who die in each potential setting vs & of people who choose to die there – need to recognise potential challenges with this data Change in IPOS score for psychological and physical symptoms (aspirational) % of people on End of Life Register completing a 'what matters to me' assessment / an advanced care plan (aspirational) Audit of the quality of what matters to me assessments	
3	All people approaching the end of life receive high quality, well-coordinated care at the right place at the right time and with the right people	% people with 3 or more unplanned admissions in the last 90 days of life with an EPACCS % people with 3 or more unplanned admissions in the last 90 days of life without an EPACCS Add into the bereaved carers survey 'how well do you think the team caring for your relative worked together' Burden of Care score (OACC measures)	Length of time getting from a request for a bed in the hospice to getting into the hospice Length of time it takes to move someone from hospital to the community once the request has been made Numbers of people transferred from hospital with fast track funding in place Number of issues reported with availability of anticipatory medicines in the community
4	People approaching the end of life and their carers are able to talk about death with those close to them and in their communities. They feel their loved ones are well supported during and after their care.	Bereaved carers survey % of people asking to die at home who achieve this Something around the dying matters survey – need to speak to public health representative. Maybe number of contacts made during dying matters week? Number of new wills written?	

Population outcomes

Groupwork

- Do you understand these outcomes?
- Do the outcomes reflect what matters to you/your family/the people you represent?
- How would you like us to demonstrate improvements against these outcomes?

Public representation and assurance

We have a legal and a moral duty to involve people in the decisions we make.

We want patients, carers and the public to be assured that we are putting people at the heart of our decision-making. We call this approach 'public assurance'.

Public representation and assurance

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For the public to feel assured we need to demonstrate we have:

Listened	We have listened to people by using existing insight or carrying out involvement activities
Acted	We have acting on feedback and used it to shape local services and plans.
Fed back	We have fed back to people and proactively telling people how we have used their feedback

Transparent & accountable

Public representation and assurance

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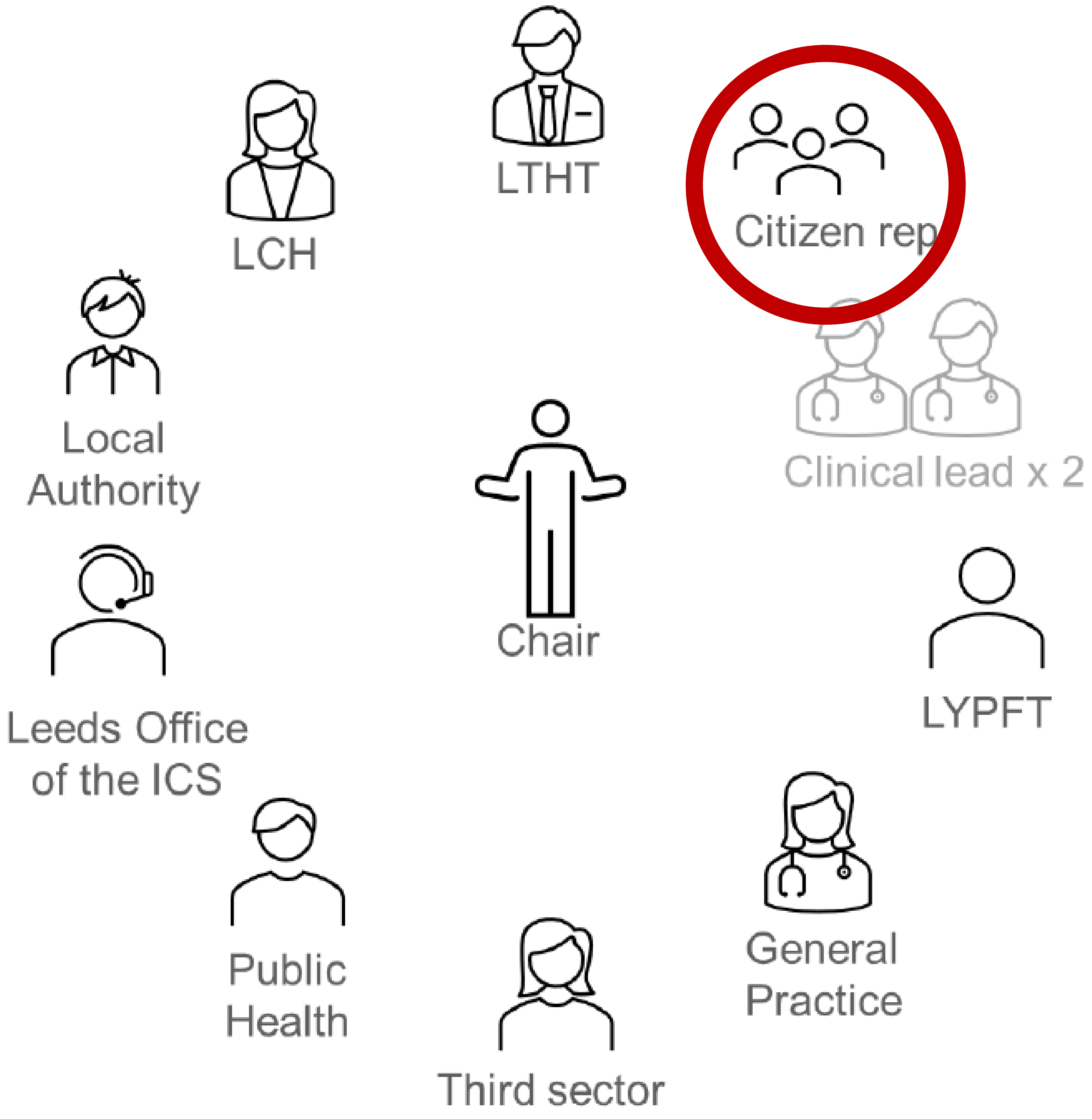
There are lots of ways we provide assurance that we have involved people in our work:

- Insight reviews
- Insight reports
- Workshops

We want to continue and build on our public assurance work. This will involve working with our partners and local people to create new ways to represent the views of patients, their families and staff on our boards.



Public representation and assurance

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Groupwork

- What do you think of the ways we are already involving people (insight reviews/workshops)?
- What does public representation look like for you?
- What would make you feel confident that we are listening, acting and feeding back?

Next steps

- Evaluation of the session
- Update insight report based on todays feedback
- Use feedback to develop an approach to representation
- Begin planning involvement on the gaps in our knowledge

Thank you

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