NATIONAL NETWORK APPROACH TO PATIENT ENGAGEMENT WORKSHOP

Wednesday 20th March 2024, College Court, Leicester

East Midlands
Congenital Heart Network
Patient and Public
Voice Volunteers

Housekeeping

1. **Fire Exits and Assembly Points**
2. **Toilets**
3. **Additional Support**
4. **Contribution and participation**
5. **Feedback**

We would appreciate your feedback on today's event.

A short feedback form can be accessed via the QR code on your table.

Many thanks.

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Welcome & Introduction

Dr Aidan Bolger

Clinical Director

East Midlands Congenital Heart Network

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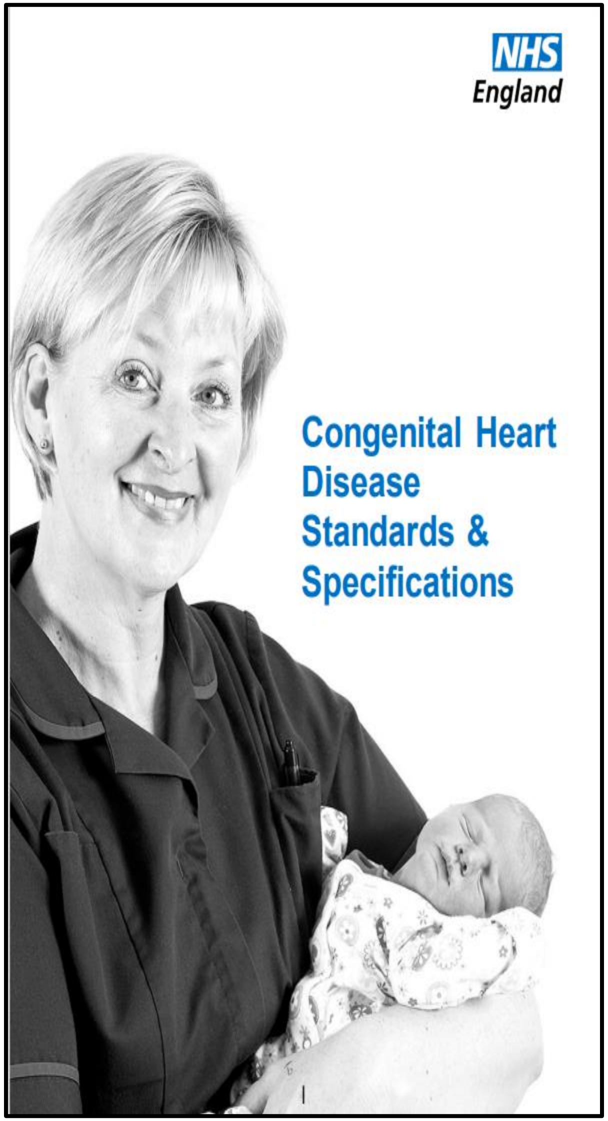
PPV: what is it??



NHS England

Congenital Heart Disease Standards & Specifications

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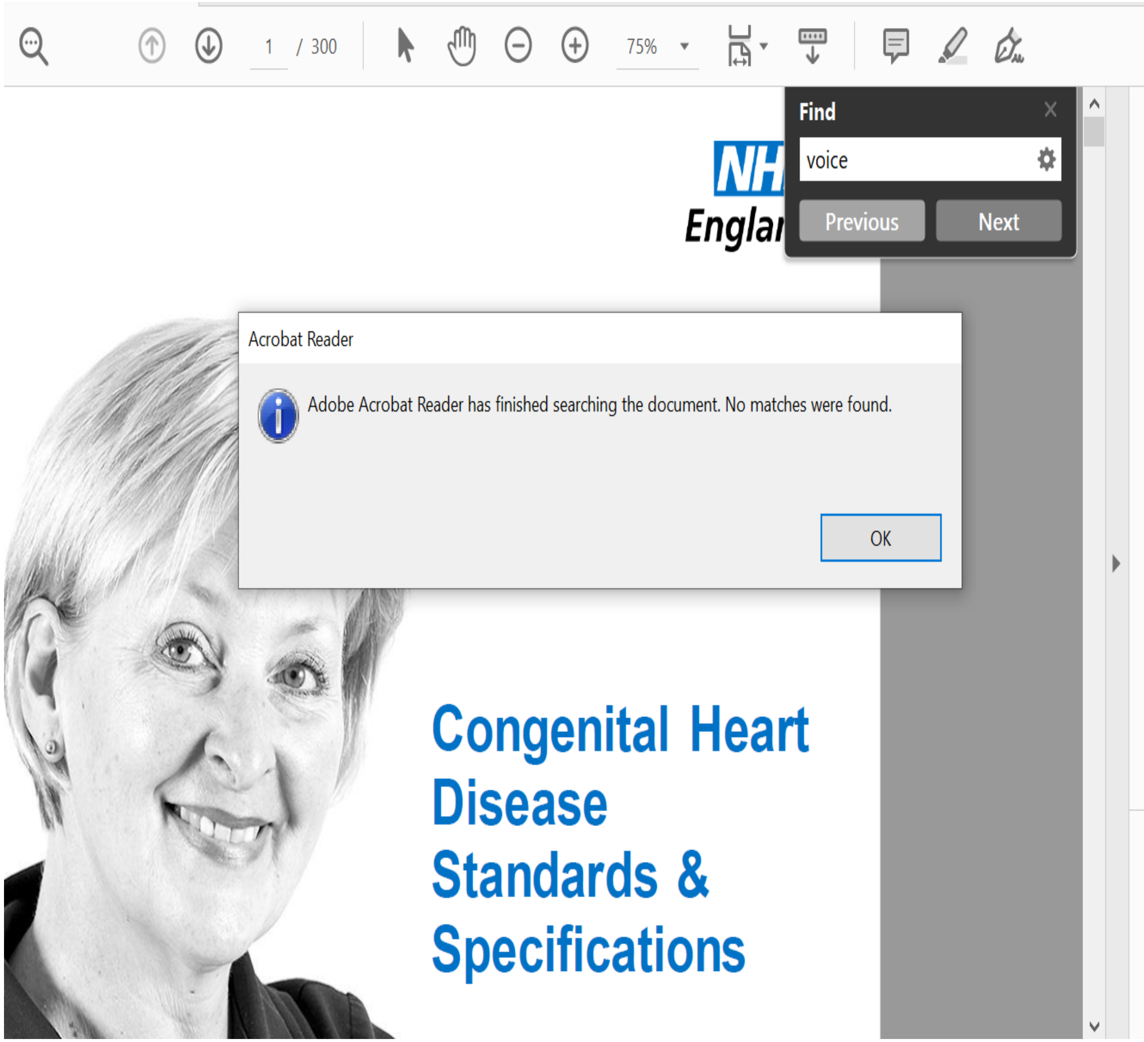

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Congenital Heart Disease Standards & Specifications

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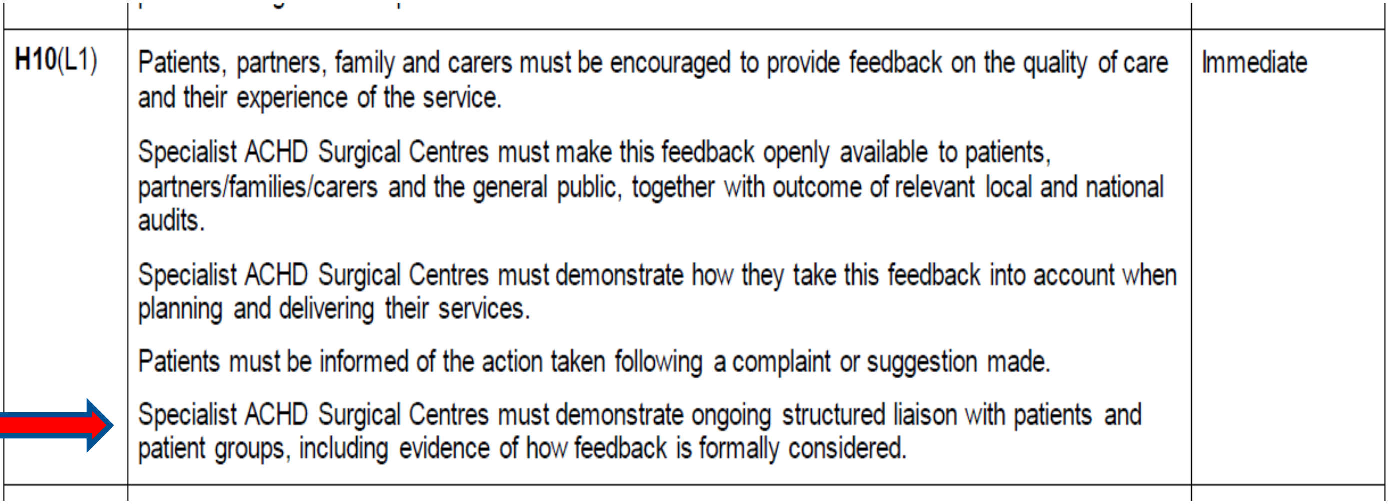
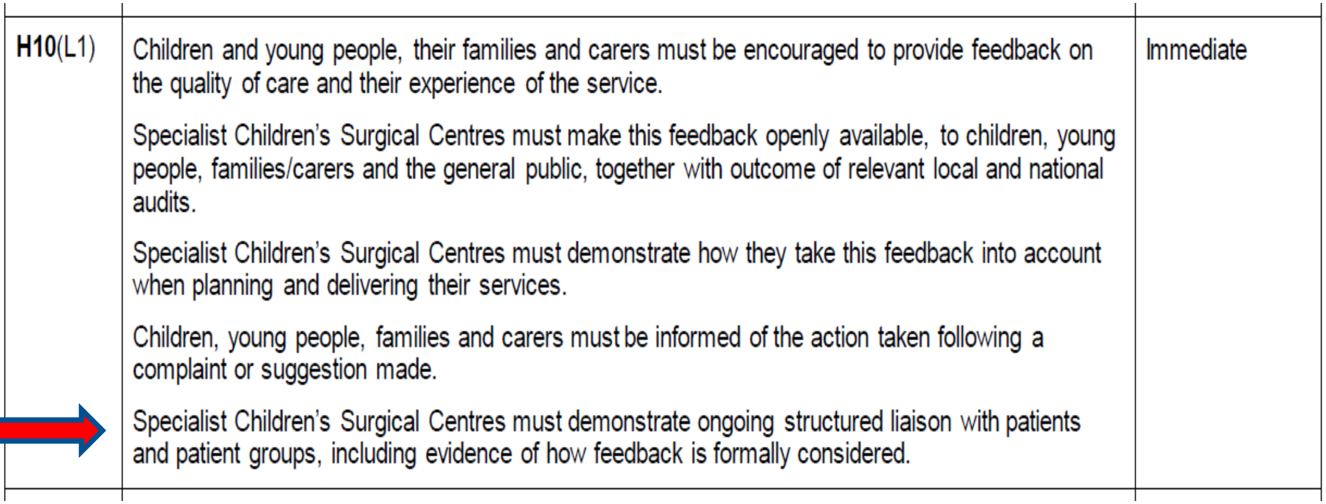


H10(L1)	Patients, partners, family and carers must be encouraged to provide feedback on the quality of care and their experience of the service. Specialist ACHD Surgical Centres must make this feedback openly available to patients, partners/families/carers and the general public, together with outcome of relevant local and national audits. Specialist ACHD Surgical Centres must demonstrate how they take this feedback into account when planning and delivering their services. Patients must be informed of the action taken following a complaint or suggestion made. Specialist ACHD Surgical Centres must demonstrate ongoing structured liaison with patients and patient groups, including evidence of how feedback is formally considered.	Immediate



H10(L1)	Children and young people, their families and carers must be encouraged to provide feedback on the quality of care and their experience of the service. Specialist Children's Surgical Centres must make this feedback openly available, to children, young people, families/carers and the general public, together with outcome of relevant local and national audits. Specialist Children's Surgical Centres must demonstrate how they take this feedback into account when planning and delivering their services. Children, young people, families and carers must be informed of the action taken following a complaint or suggestion made. Specialist Children's Surgical Centres must demonstrate ongoing structured liaison with patients and patient groups, including evidence of how feedback is formally considered.	Immediate

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"feedback"

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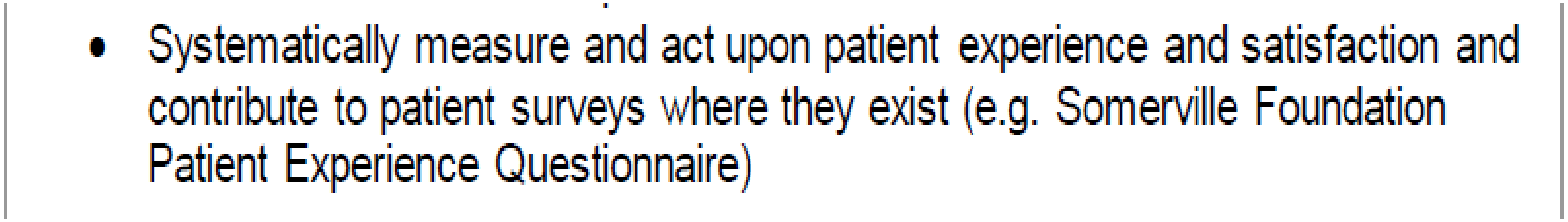
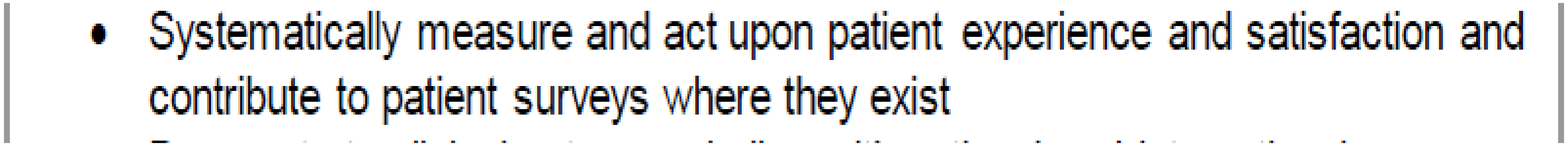
SURVEY RESEARCH CENTER
ELEVATOR
UP
UNDECIDED
DOWN
SCHWADRON



- Systematically measure and act upon patient experience and satisfaction and contribute to patient surveys where they exist (e.g. Somerville Foundation Patient Experience Questionnaire)



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“surveys”

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Patient surveys

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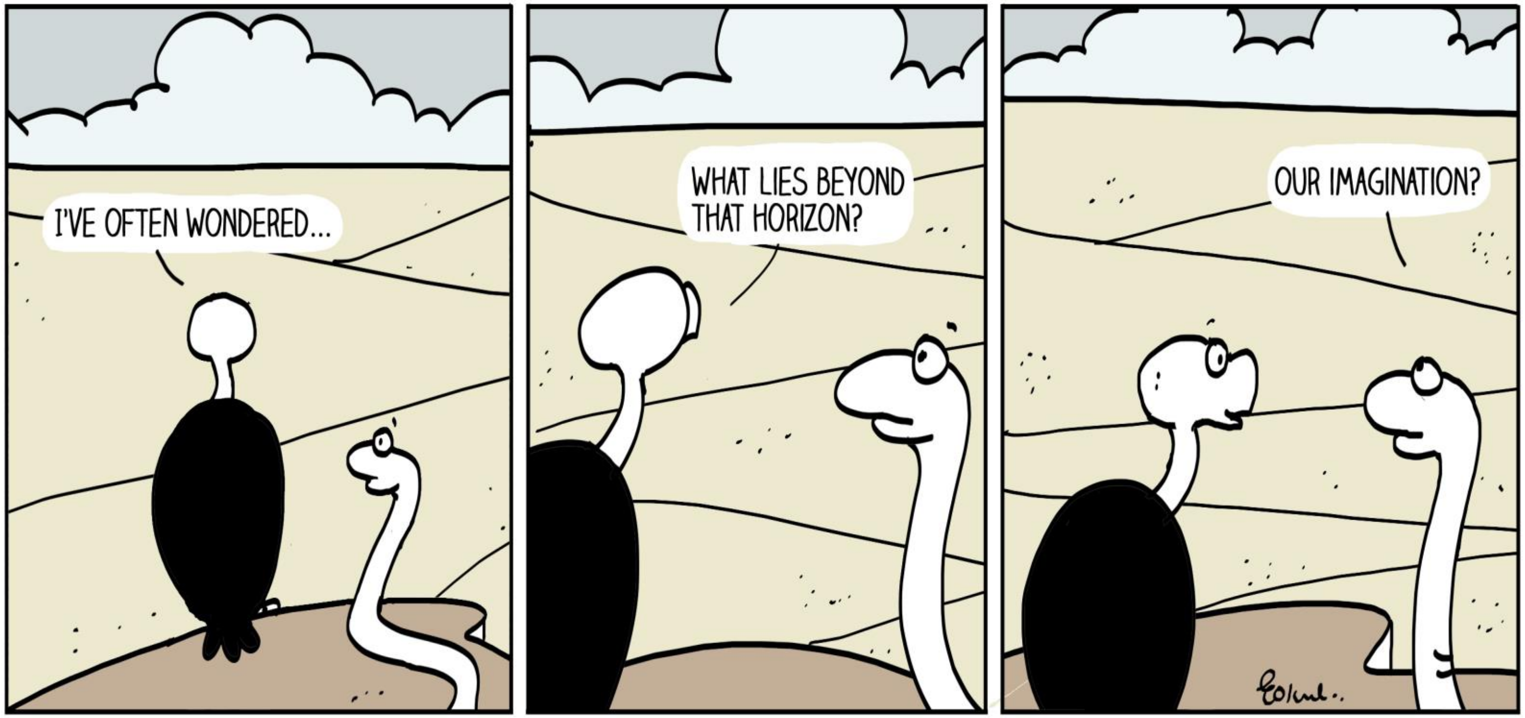
Patient surveys

What lies beyond the survey?



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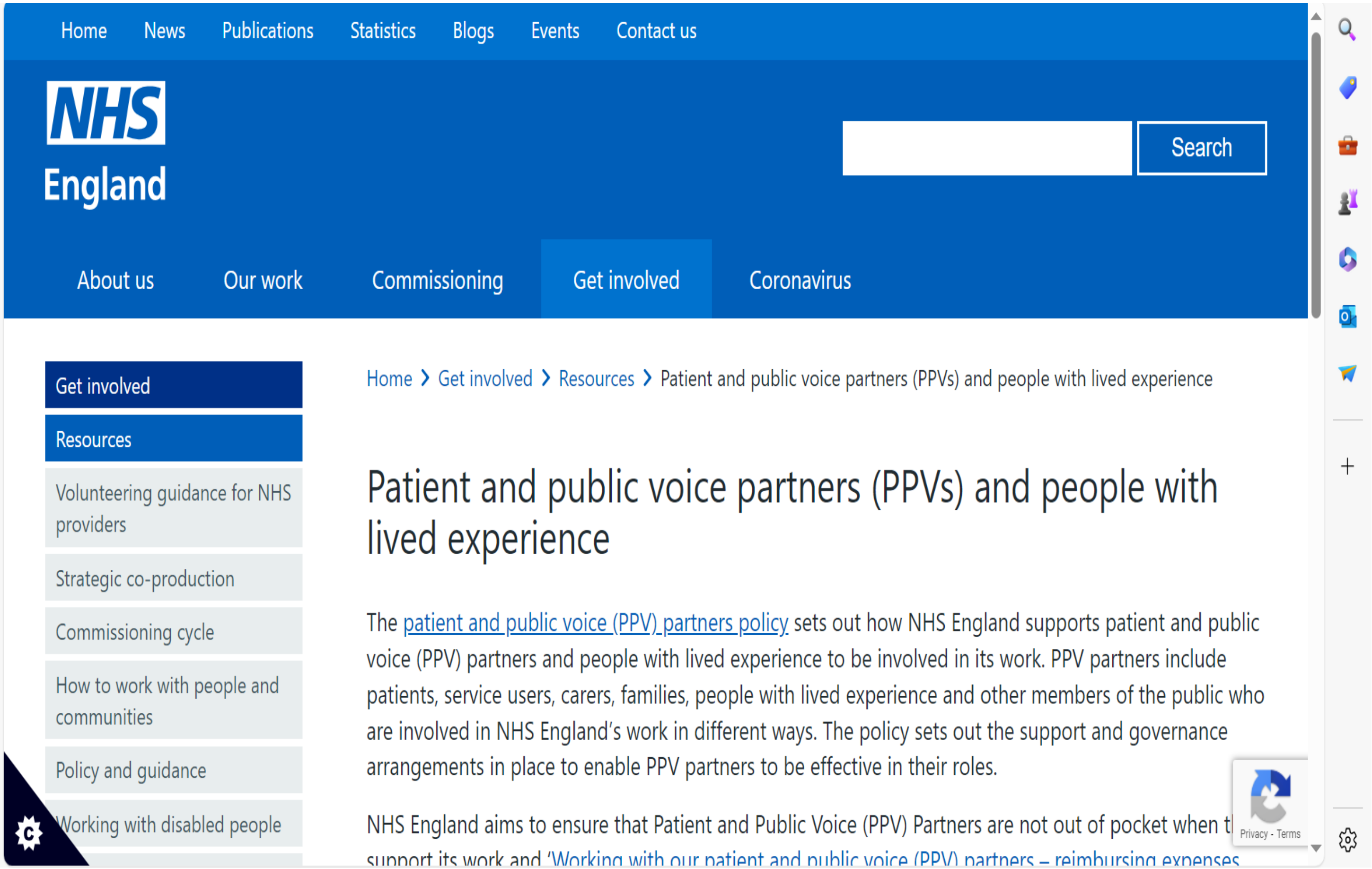

Patient and public voice partners (PPVs) and people with lived experience

The patient and public voice (PPV) partners policy sets out how NHS England supports patient and public voice (PPV) partners and people with lived experience to be involved in its work. PPV partners include patients, service users, carers, families, people with lived experience and other members of the public who are involved in NHS England's work in different ways. The policy sets out the support and governance arrangements in place to enable PPV partners to be effective in their roles.

NHS England aims to ensure that Patient and Public Voice (PPV) Partners are not out of pocket when t
support its work and 'Working with our patient and public voice (PPV) partners – reimbursing expenses

https://www.england.nhs.uk/get-involved/resources/patient-public-voice-par

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self-management education

strategic co-production

Active listening

Facilitative leadership

lived experience

Empowering people

meaningful co-production

Balancing personal power and positional power

This acronym buster might be helpful alongside our understanding the NHS section

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Why are we here?

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Why?

What?

Who?

When?

How?

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What does AI think?

Why is patient engagement important?

Patient engagement is crucial for several reasons:

Improved Health Outcomes

Engaged patients are more likely to adhere to treatment plans, follow preventive measures, and actively participate in managing their health conditions, leading to better health outcomes.

Enhanced Patient Satisfaction

When patients are actively involved in their care, they feel more satisfied with the healthcare experience. This can lead to higher patient retention rates and positive feedback for healthcare providers

Better Communication

Engaged patients tend to have better communication with their healthcare providers, leading to more accurate diagnosis, tailored treatment plans, and fewer medical errors.

Cost Reduction

By actively participating in their care and adopting preventive measures, engaged patients can help reduce healthcare costs associated with preventable conditions, unnecessary hospital readmissions, and avoidable emergency room visits.

Empowerment and Self-Management

Patient engagement empowers individuals to take control of their health, make informed decisions, and manage chronic conditions effectively, leading to improved quality of life.

Research and Development

Engaged patients may participate more willingly in clinical trials and research studies, contributing valuable data and insights to advance medical knowledge and develop innovative treatments

Co-production

What does co-production in heath care mean?

Co-production in healthcare refers to an approach where healthcare providers and patients work together as equal partners to design, deliver, and improve healthcare services. It involves healthcare professionals collaborating with patients, families, caregivers, and communities to ensure that services meet the needs and preferences of those who use them. This approach recognizes the expertise and insights of patients and their families and seeks to involve them in decision-making processes, treatment planning, and service evaluation. By fostering collaboration between healthcare providers and service users, co-production aims to improve the quality, effectiveness, and outcomes of healthcare services.

How do we achieve good co-production?

Achieving good co-production in the NHS involves several key strategies:

Culture of Collaboration

Foster a culture within healthcare organizations that values the input and participation of patients, families, and communities in decision-making processes.

Patient Engagement

Actively involve patients, families, and caregivers in all stages of healthcare delivery, from service design to evaluation. This can include inviting patients to participate in advisory groups, focus groups, or quality improvement initiatives.

Education & Training

Provide healthcare professionals with training on how to effectively engage with patients and collaborate with them as partners in care. This includes communication skills, empathy training, and cultural competence.

Shared Decision Making

Implement shared decision-making processes that empower patients to participate in decisions about their care, including treatment options, goals, and preferences.

Accessible Information

Ensure that healthcare information is presented in a clear, understandable manner and is readily accessible to patients and their families. This can include providing written materials, educational videos, and online resources.

Feedback Mechanisms

Establish mechanisms for patients to provide feedback on their experiences with healthcare services and for healthcare providers to incorporate this feedback into service improvement efforts

Partnerships & Co-design

Collaborate with patients, families, and community organizations in the co-design of healthcare services, facilities, and programs to ensure that they meet the diverse needs of the population.

Continuous Improvement

Continuously evaluate and refine co-production initiatives based on feedback and outcomes data to ensure that they are effectively meeting the needs of patients and improving the quality of care

Partnerships & Co-design

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Achieving good co-production in the NHS involves several key strategies:

By implementing these strategies, the NHS can create a culture of co-production where patients are active partners in their care, leading to more **patient-centered**, **effective**, and **equitable** healthcare services.

Seldom-heard Groups

How do we reach seldom heard groups across the NHS?

Reaching seldom heard groups across the NHS involves proactive and targeted approaches to engage with populations that may face barriers to accessing healthcare services or participating in decision-making processes. Here are some strategies:

Community Outreach

Establish partnerships with community organizations, religious institutions, and local leaders to reach out to seldom heard groups directly in their communities. This can involve hosting information sessions, health fairs, and outreach events in community settings.

Cultural Competence

Train healthcare professionals to understand and respect the cultural beliefs, values, and practices of diverse populations. This can help build trust and rapport with seldom heard groups and improve communication and engagement.

Language Access

Provide language interpretation and translation services to ensure that healthcare information is accessible to individuals with limited English proficiency. This includes offering interpretation services during clinical visits and translating written materials into multiple languages.

Tailored Communication

Develop culturally and linguistically appropriate communication materials that resonate with the needs and preferences of seldom heard groups. This may involve using plain language, visual aids, and storytelling to convey health information effectively.

Peer Support

Recruit and train peer educators or community health workers from seldom heard groups to serve as liaisons between healthcare providers and their communities. These individuals can help bridge cultural and linguistic barriers and provide support and advocacy for community members.

Flexible Service Delivery

Offer flexible appointment scheduling, transportation assistance, and other support services to accommodate the needs of seldom heard groups, such as those with limited mobility or transportation options.

Participatory Approaches

Engage seldom heard groups in participatory research, quality improvement initiatives, and co-design processes to ensure that healthcare services are responsive to their needs and preferences.

Data Collection & Monitoring

Collect demographic data on patient populations served by the NHS to identify disparities in access and outcomes among seldom heard groups. Use this data to inform targeted interventions and monitor progress over time.

Seldom-heard Groups

By implementing these strategies, the NHS can improve access to healthcare services and outcomes for seldom heard groups, ultimately advancing health equity and reducing disparities in healthcare delivery

Listening to and working with women and families using maternity & neonatal services

Presented by:
Lisa Ramsey, Service User Voice Policy Manager,
Maternity & Neonatal Programme, NHS England

Three Year Delivery Plan for Maternity & Neonatal services

‘This plan sets out how the NHS will make maternity and neonatal care safer, more personalised, and more equitable for women, babies, and families.’

‘While the birth of a baby represents the happiest moment of many people’s lives, some families have experienced unacceptable care, trauma, and loss, and with incredible bravery have rightly challenged the NHS to impr

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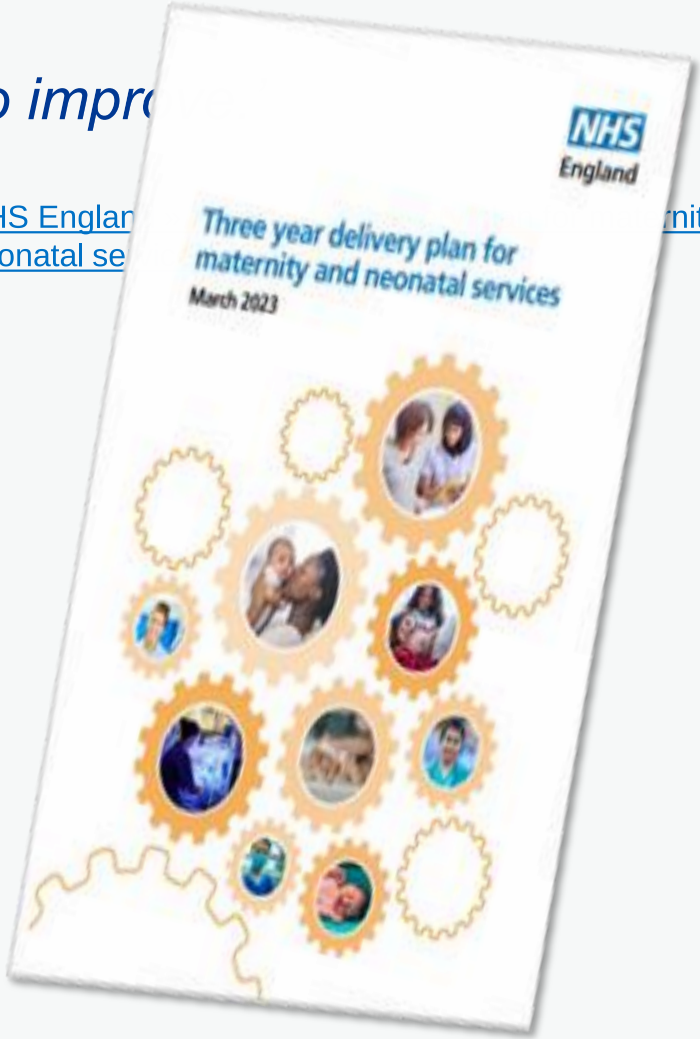
neonatal se



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Three year delivery plan for maternity and neonatal services
March 2023

Three Year Delivery Plan – an overview

[NHS England » Three-year delivery plan for maternity and neonatal services]

NHS

1 Listening to and working with women and families with compassion

- Care that is personalised
- Improve equity for mothers and babies
- Working with service users to improve care

2 Growing, retaining and supporting our workforce

- Growing our workforce at all levels
- Valuing and retaining our workforce
- Investing in and accrediting skills

3 Developing a culture of safety, learning and support

- Developing a positive safety culture
- Learning and improving
- Support and Oversight

4 Standards and structures that underpin safer, more personalised, and more equitable care.

- Standards to ensure best practice
- Data to inform learning
- Digital

How do we work with service users to improve care?

A maternity and neonatal voices partnership listens to the experiences of women and families, and brings together service users, staff, and other stakeholders to plan, review and improve maternity and neonatal care. MNVPs ensure that service user voice is at the heart of decision-making in maternity and neonatal services by being embedded within the leadership of provider trusts and feeding into the LMNS. This influences improvements in the safety, quality, and experience of maternity and neonatal care.

The vision for maternity and neonatal voices partnerships

1.19 Our ambition is:

- *MNVPs listen to and reflect the views of local communities. All groups are heard, including bereaved families.*
- *MNVPs have strategic influence and are embedded in decision-making.*
- *MNVPs have the infrastructure they need to be successful. Workplans are funded. MNVP leads, formerly MVP chairs, are appropriately employed or remunerated and receive appropriate training, administrative and IT support.*

1.20 In addition, neonatal parental advisory groups represent service user experience as part of operational delivery networks.

NHS England » Three-year delivery plan for maternity and neonatal services

How will this happen?

*1.21 It is the responsibility of **trusts** to:*

- *Involve service users in quality, governance, and co-production when designing and planning delivery of maternity and neonatal services.*

*1.22 It is the responsibility of **ICBs** to:*

- *Commission and fund MNVPs, to cover each trust within their footprint, reflecting the diversity of the local population in line with the ambition above.*
- *Remunerate and support MNVP leads and ensure that a funded workplan is agreed.*
- *Ensure service user representatives are members of the local maternity and neonatal system (LMNS) board.*

*1.23 **NHS England** will:*

- *Co-produce national policy and quality improvement initiatives with service user representatives and MNVP leads.*
- *Through operational delivery networks (ODNs), support parent representation in the governance of neonatal services.*
- *Provide funding for clinical leadership and programme management of ICBs, which includes funding to support service user involvement.*

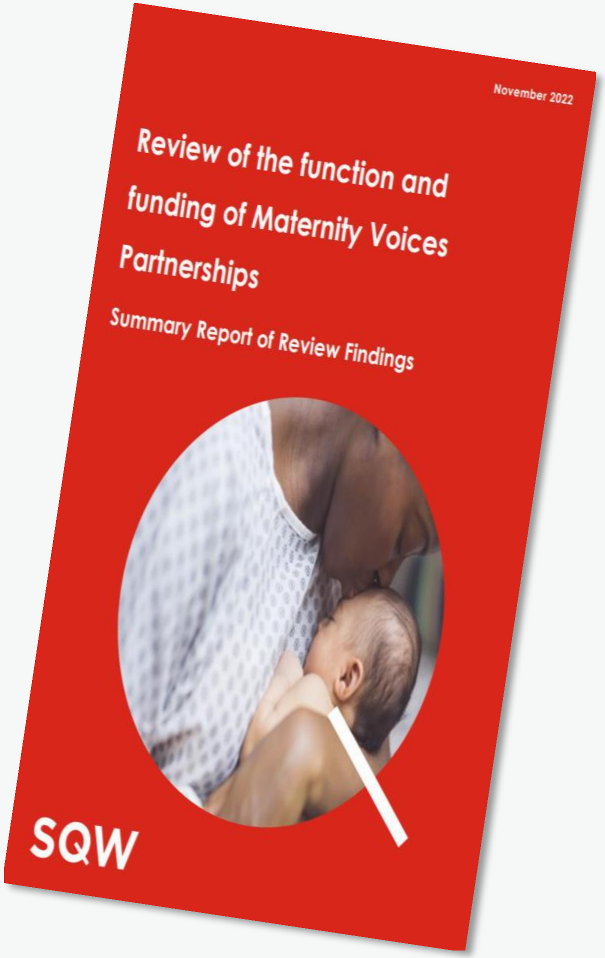
NHS England » Three-year delivery plan for maternity and neonatal services

2022 MNVP Function & Funding Review

The 2022 Review of the Funding and Function of Maternity Voices Partnerships (NHS Futures) identified:

“*a high degree of **variation** in the way MVPs are implemented across England... that the presence and extent of key enablers [for an effective MVP] vary… In addition, the role of MVPs has evolved, and expectations placed on them have grown as a result. However, a lack of consistency in MVP resourcing and in the provision of training and support pose considerable challenges for MVP functioning.*”

The principles outlined in the MNVP Guidance will help ICBs and trusts address unwarranted variation, while ensuring there remains flexibility to design MNVPs around the needs of local women and families.



November 2022

Review of the function and funding of Maternity Voices Partnerships

Summary Report of Review Findings

SQW

MNVP Guidance

This document provides advice to Integrated Care Boards (ICB) and trusts to fulfil their statutory obligations to involve people and communities in the planning, proposals and decisions regarding NHS maternity and neonatal services in England and to respond to the actions and responsibilities laid out in the Three-Year Delivery Plan for Maternity and Neonatal Services.

Classification: Official

NHS England

Maternity and neonatal voices partnership guidance

Publication reference: PRN00823_i

MNVP Guidance conte

The MNVP Guidance gives clear direction on what an MNVP is and how ICBs can commission effective MNVPs.

Maternity and neonatal voices partnership guidance

Contents

2

The addition of neonatal voices

In May 2022, NHS England published Next steps towards LMNS (FutureNHS), which sets out plans for greater integration of maternity and neonatal transformation. It states:

- *Local service users are co-production partners in maternity/neonatal quality and transformation: the voices of neonatal parents can be heard through either an MVP or PAG (parent advisory group).*
- *LMNS has a clear process for hearing from parents who have received neonatal care and for involving them in co-production work as appropriate.*

MNVPs and PAGs will need to develop relationships and work together to ensure neonatal voices are represented at both operational delivery network level and at local level .

Framework for effective MNVPs

1. OPERATIONAL AND LOGISTICAL SUPPORT

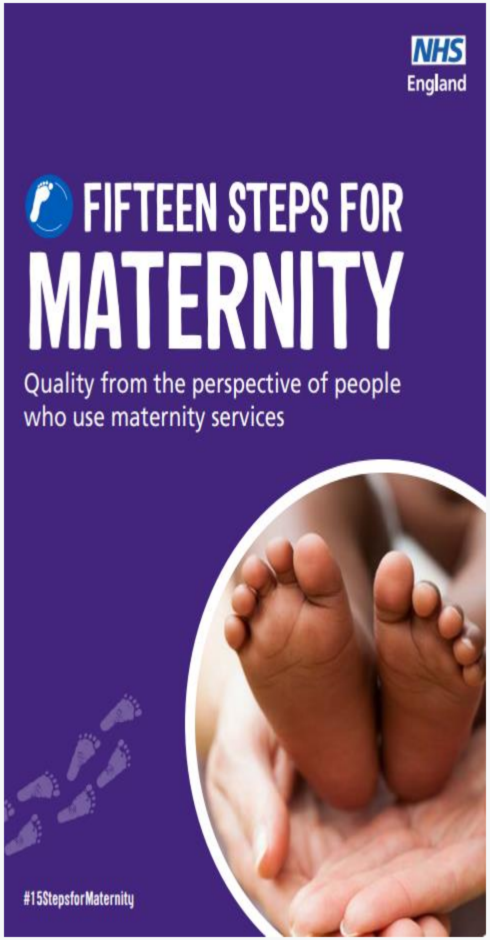
- Every MNVP has a service user Lead to lead the MNVP programme of work, who is appropriately remunerated for the role, and
- Every MNVP has an agreed workplan which is funded

2. ENGAGEMENT

- Every MNVP listens well to women and families e.g., [NHS England » The Fifteen Steps for Maternity – Quality from the perspective of people who use maternity services]

3. STRATEGIC INFLUENCE

- Every MNVP has strategic influence at trust level and service users have strategic influence at LMNS level



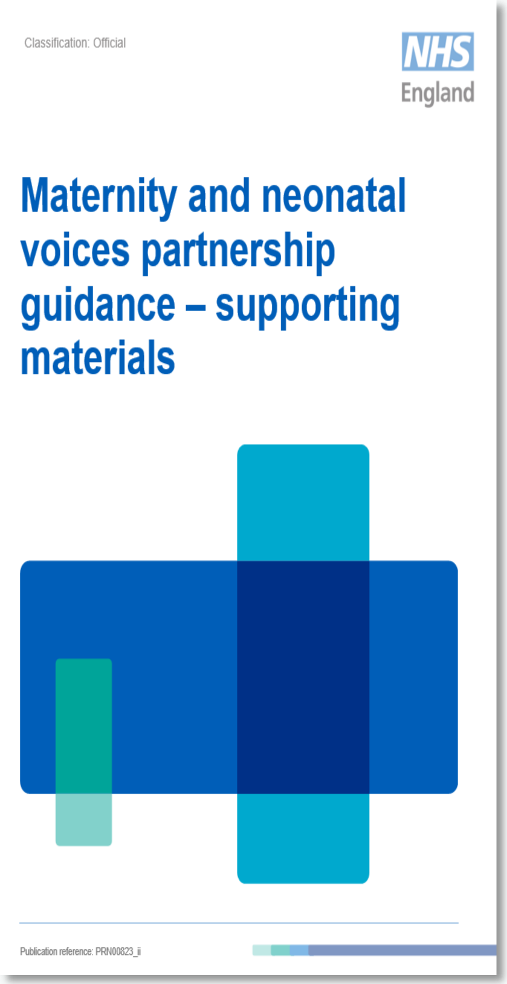
NHS
England

FIFTEEN STEPS FOR
MATERNITY

Quality from the perspective of people who use maternity services

#15StepsforMaternity

MNVP Guidance Supporting Materials and FAQs

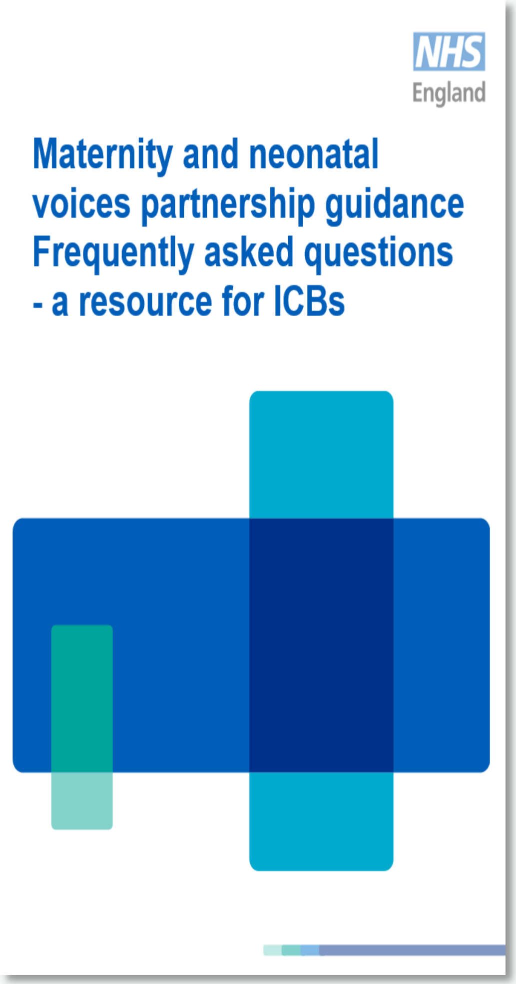


Classification: Official

NHS England

Maternity and neonatal voices partnership guidance – supporting materials

Publication reference: PRN00823_ii



NHS England

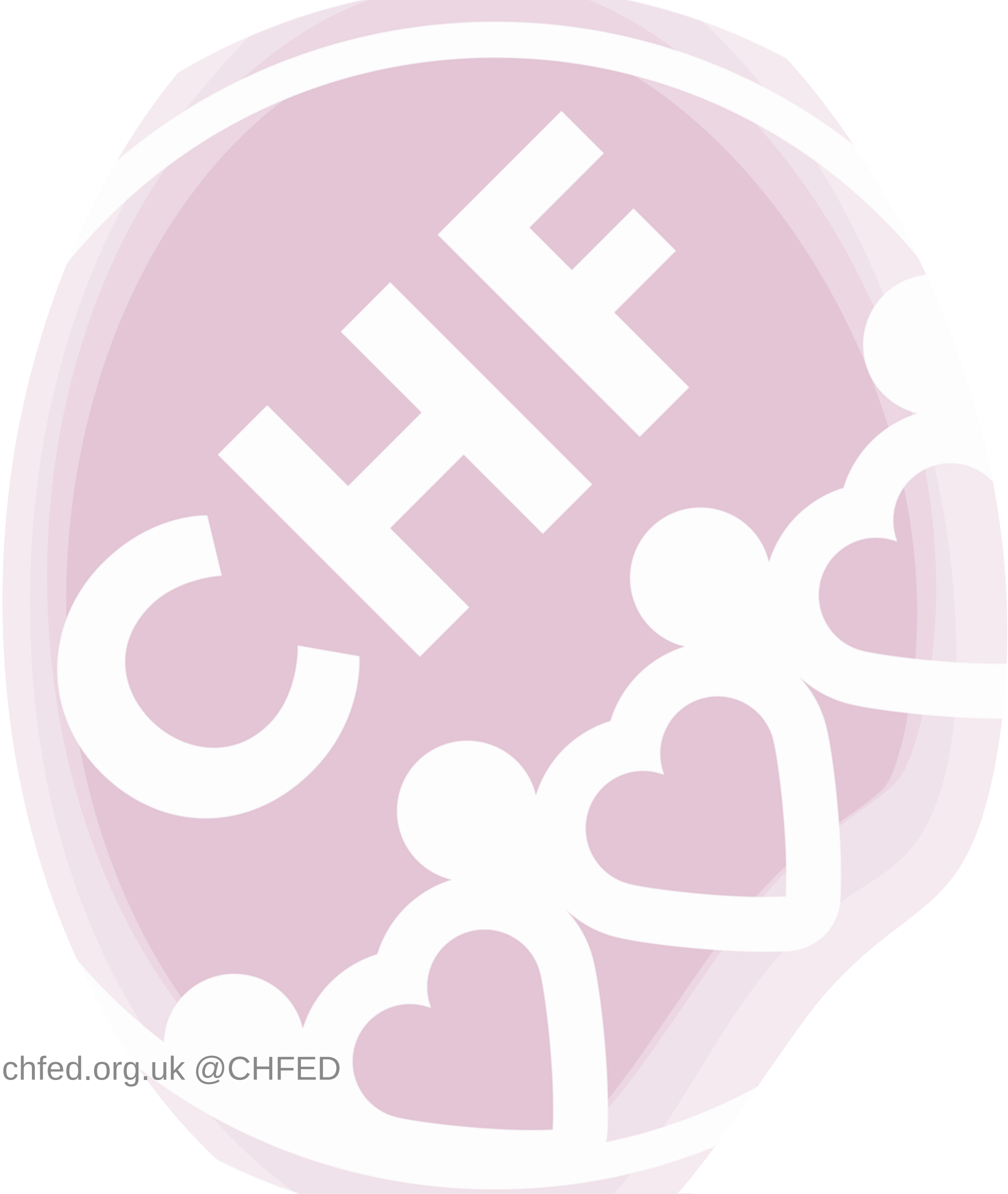
Maternity and neonatal voices partnership guidance Frequently asked questions - a resource for ICBs

Thank You

@nhsengland

company/nhsengland

england.nhs.uk



rajwant@chfed.org.uk @CHFED

How we help

The Children’s Heart Federation (CHF) is the leading national charity championing children with heart conditions.

CHF is dedicated in empowering these children, their families, and carers.

Leading the way for heart children

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@CHFED

- **Our vision** is that all children with heart conditions have their medical and social needs met so they can live the fullest life possible.

- **Our mission** is to provide **recognition, research, and resources** to support those affected by children's heart conditions.

- We work collaboratively with individuals and organisations to **inform, inspire and improve** the lives of children with congenital and acquired heart disease

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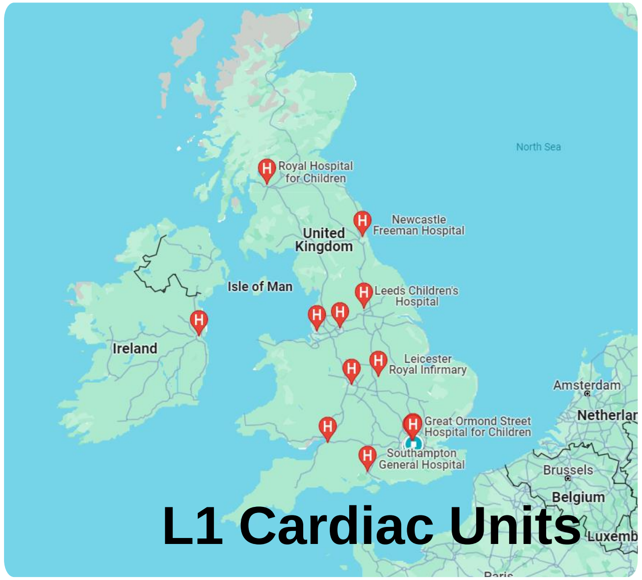
National



L1 Cardiac Units

Partner Groups

- Children with heart conditions their families and carers
- 40 partner charities
- All level 1 Cardiac Units, CHD Networks, CRG, local ICB and beyond
- 3 Steering Groups
- International groups
- New business plan working towards equitable support across the country

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Equity & Accessibility

- Information sheets – QR code posters, translations – video content
- Helpline – 24/7 & bilingual speakers
- Coffee & Questions – talks to workshops
- Utility bills review

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PPV's – what we hear

Lived experience is just a **part** of who we are?

I want to pay back the team who did so much for us

Is this relevant to me? PPV?

We're not hearing from everyone

This is not a forum to complain

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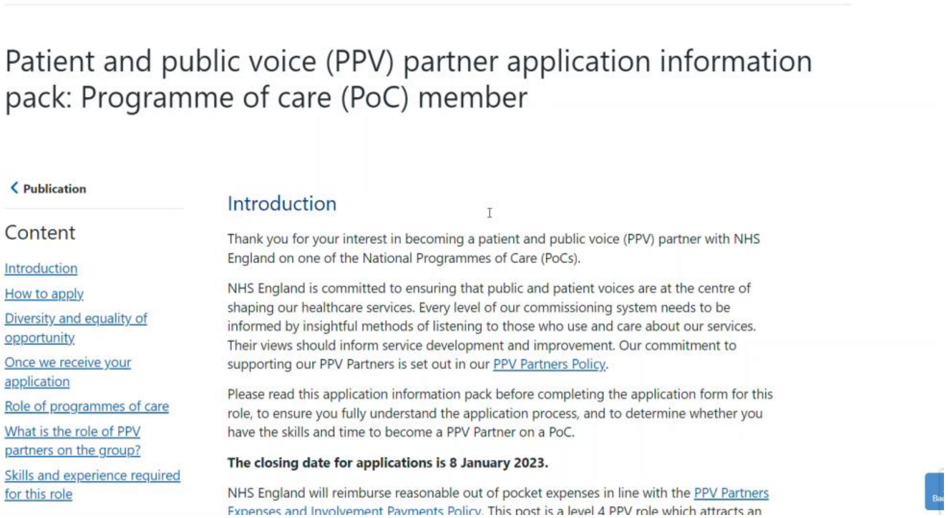
PPV's Back to basics



Patient and public voice (PPV) partner application information pack: Programme of care (PoC) member

Content

Introduction

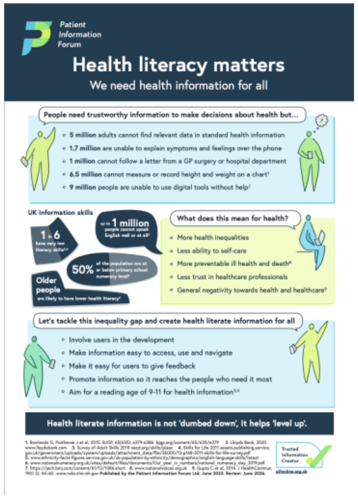
Thank you for your interest in becoming a patient and public voice (PPV) partner with NHS England on one of the National Programmes of Care (PoCs).

NHS England is committed to ensuring that public and patient voices are at the centre of shaping our healthcare services. Every level of our commissioning system needs to be informed by insightful methods of listening to those who use and care about our services. Their views should inform service development and improvement. Our commitment to supporting our PPV Partners is set out in our PPV Partners Policy.

Please read this application information pack before completing the application form for this role, to ensure you fully understand the application process, and to determine whether you have the skills and time to become a PPV Partner on a PoC.

The closing date for applications is 8 January 2023.

NHS England will reimburse reasonable out of pocket expenses in line with the PPV Partners Expenses and Involvement Payments Policy. This post is a level 4 PPV role which attracts an



Patient Information Forum

Health literacy matters

We need health information for all

People need trustworthy information to make decisions about health but...

- **5 million** adults cannot find relevant data in standard health information
- **1.7 million** are unable to explain symptoms and feelings over the phone
- **1 million** cannot follow a letter from a GP surgery or hospital department
- **6.5 million** cannot measure or record height and weight on a chart[1]
- **9 million** people are unable to use digital tools without help[2]

UK information skills

What does this mean for health?

- More health inequalities
- Less ability to self-care
- More preventable ill health and death[8]
- Less trust in healthcare professionals
- General negativity towards health and healthcare[9]

Let's tackle this inequality gap and create health literate information for all

- Involve users in the development
- Make information easy to access, use and navigate
- Make it easy for users to give feedback
- Promote information so it reaches the people who need it most
- Aim for a reading age of 9-11 for health information[3,4]

Health literate information is not 'dumbed down', it helps 'level up'.

Published by the Patient Information Forum Ltd. June 2023. Review: June 2026.

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PPV's – how we can help RECRUITMENT

- We are already in these spaces – join us online and in person
- Don't underestimate 'peer power'
- Accessible formatting - review job descriptions & information shared
- Learn from what we're doing – allow multiple ways to apply - 'survey' forms or video responses
- Personal contact - ask

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PPV's – how we can help
MANAGEMENT

- Sharing best practice - don't hold meetings during working hours
- Make the process more dynamic – experience mapping / patient experience questionnaires - Wooclap
- Build agendas collaboratively and share information respectfully
- Local partner charities on each PPV

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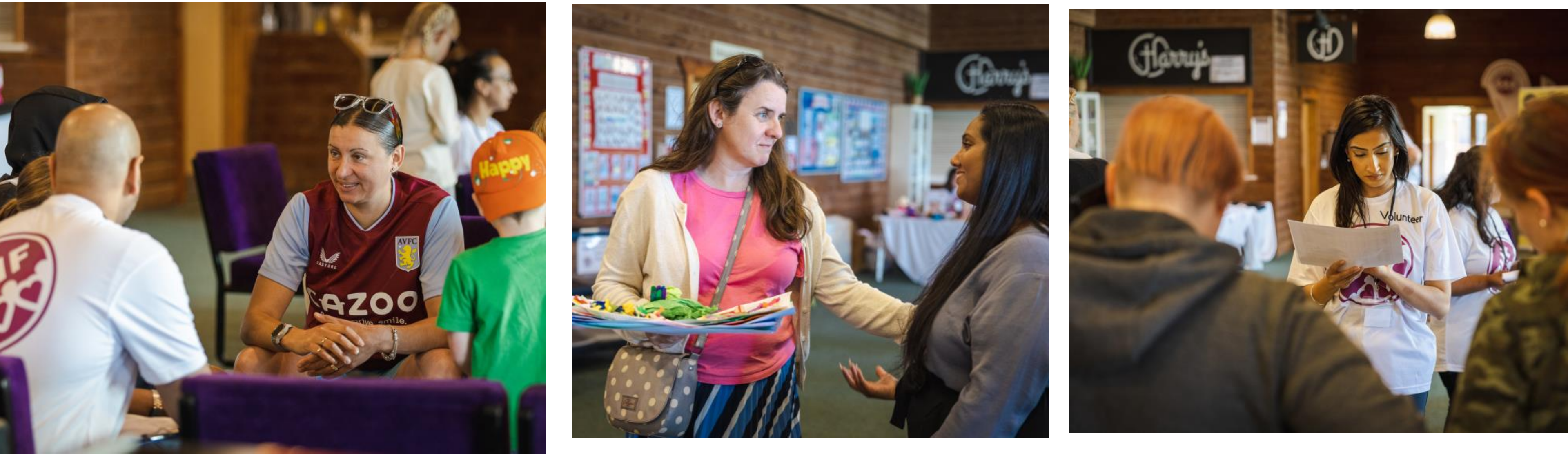

PPV's – how we can help TRAINING

- Understanding agendas and data
- Meeting etiquette and expectations
- Voicing personal concerns
- Emotional resilience

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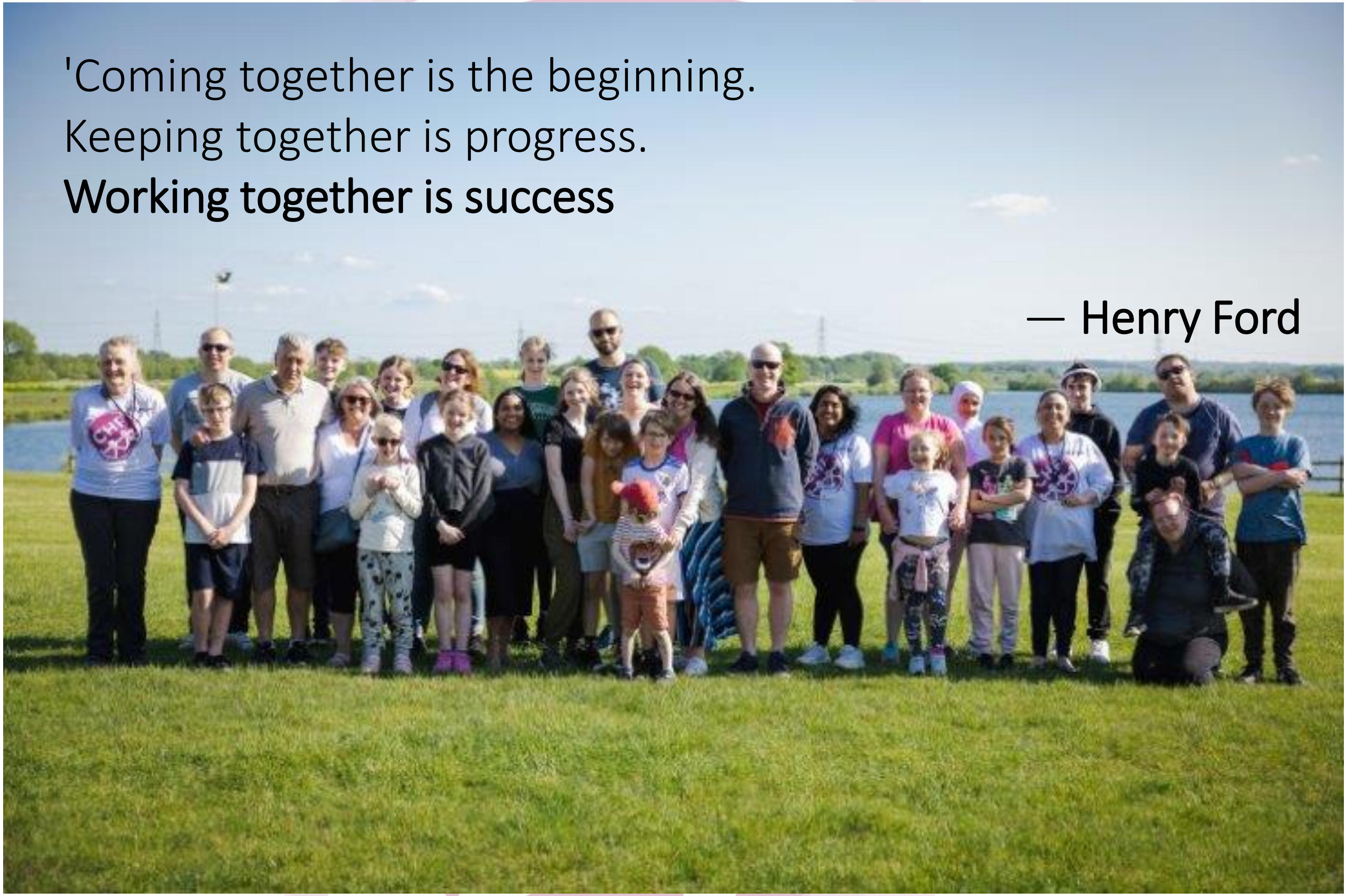

'Coming together is the beginning.
Keeping together is progress.
Working together is success

— Henry Ford

CHD Network Gap Analysis

Good Practice:

- A range a patient surveys which cover elements of outpatients and inpatient services
- Recruitment templates
- PPV meeting governance
- Video Resources

Gaps

- Gaining feedback from a range of patients, opposed to just PPV reps
- PPV recruitment – process and management
- PPV Training packages
- Fetal experiences
- BAME representation
- LD inclusion

Agreeing Key Priorities

Lets get started:

- What are the must do’s?
- What could be shared to become a national approach out of the good practice that Networks already have?
- What could we work on collectively today?
- What should we commit to achieving?

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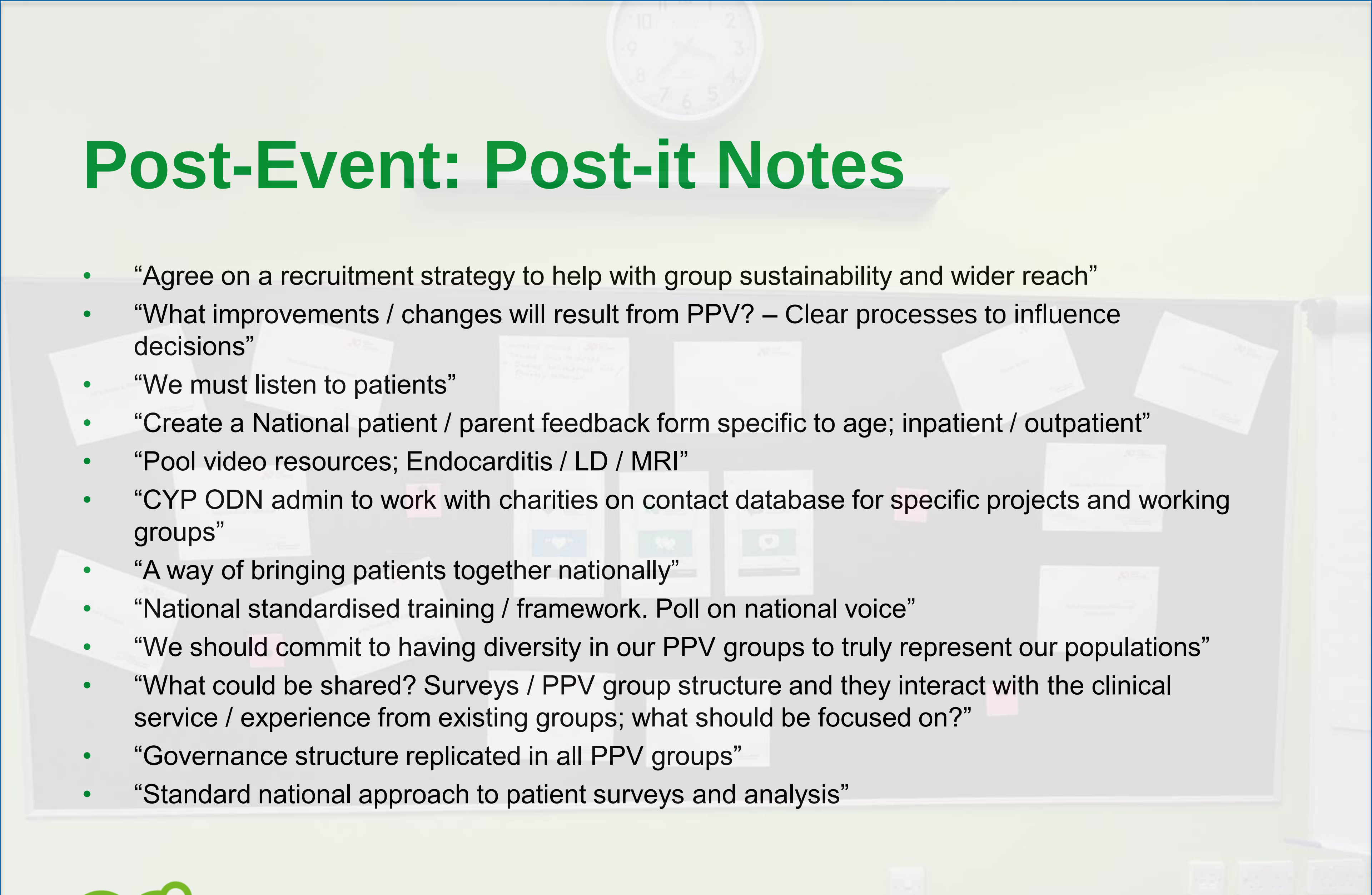

Post-Event: Post-it Notes

- “Agree on a recruitment strategy to help with group sustainability and wider reach”
- “What improvements / changes will result from PPV? – Clear processes to influence decisions”
- “We must listen to patients”
- “Create a National patient / parent feedback form specific to age; inpatient / outpatient”
- “Pool video resources; Endocarditis / LD / MRI”
- “CYP ODN admin to work with charities on contact database for specific projects and working groups”
- “A way of bringing patients together nationally”
- “National standardised training / framework. Poll on national voice”
- “We should commit to having diversity in our PPV groups to truly represent our populations”
- “What could be shared? Surveys / PPV group structure and they interact with the clinical service / experience from existing groups; what should be focused on?”
- “Governance structure replicated in all PPV groups”
- “Standard national approach to patient surveys and analysis”

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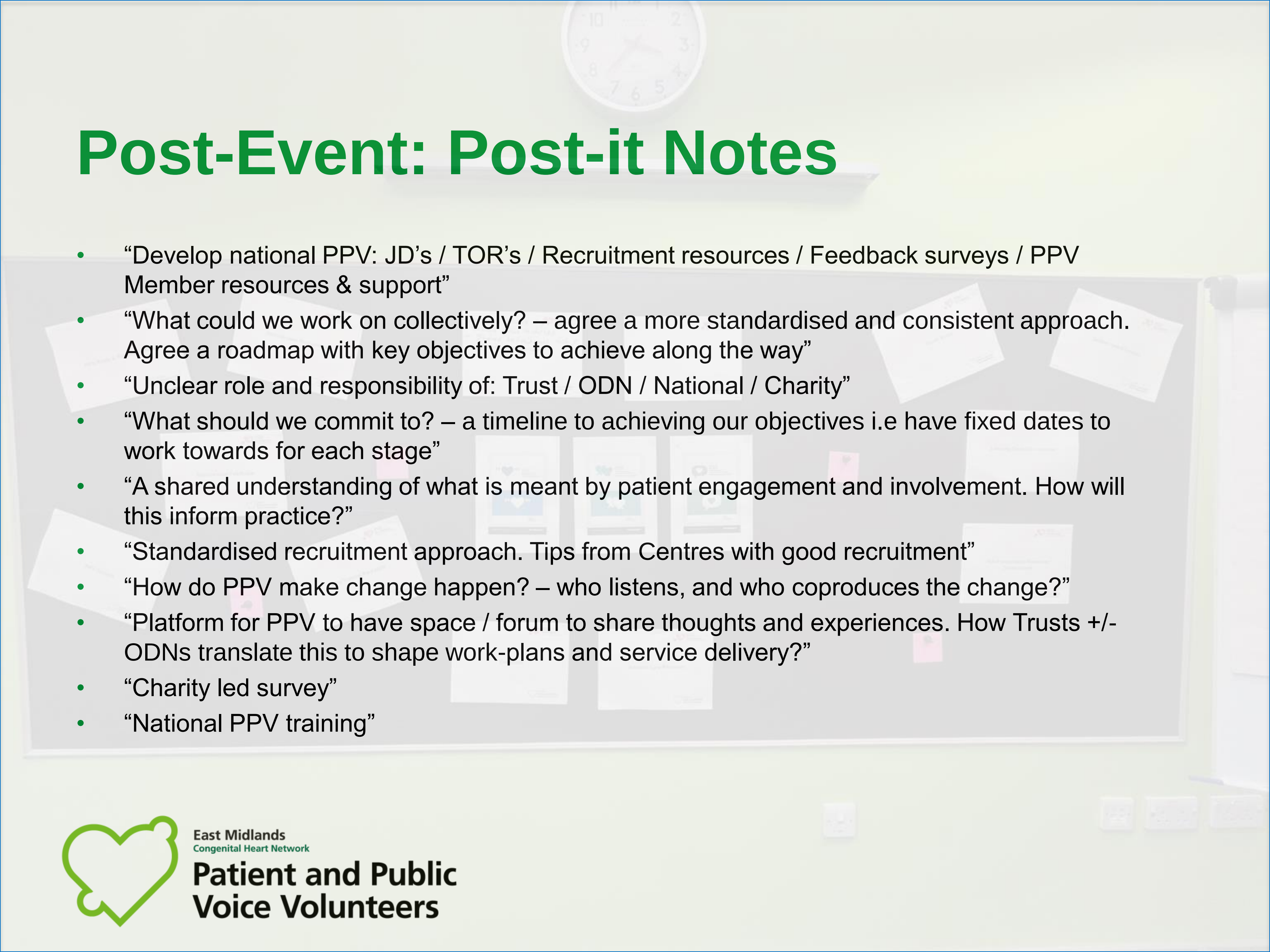
Post-Event: Post-it Notes



- “Develop national PPV: JD’s / TOR’s / Recruitment resources / Feedback surveys / PPV Member resources & support”
- “What could we work on collectively? – agree a more standardised and consistent approach. Agree a roadmap with key objectives to achieve along the way”
- “Unclear role and responsibility of: Trust / ODN / National / Charity”
- “What should we commit to? – a timeline to achieving our objectives i.e have fixed dates to work towards for each stage”
- “A shared understanding of what is meant by patient engagement and involvement. How will this inform practice?”
- “Standardised recruitment approach. Tips from Centres with good recruitment”
- “How do PPV make change happen? – who listens, and who coproduces the change?”
- “Platform for PPV to have space / forum to share thoughts and experiences. How Trusts +/- ODNs translate this to shape work-plans and service delivery?”
- “Charity led survey”
- “National PPV training”

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Post-Event: Post-it Notes

- “Recruitment: Create a video for Social media”
- “Paperwork governance”
- “Continuity”
- “More video content for informational purposes using patients / parents / carers”
- “Template JDs / Application form & process”
- “Explore a national approach to PPV recruitment”
- “Must-do’s: How to recruit? What questions surveys should include?”
- “What can be shared? Where is it held?”
- “I would really value a shared, user-friendly PPV training package”
- “CHF and Somerville lead training”
- “Face-to-face National PPV meeting; CHF can lead”
- “Clearer specifications at ODN level. ?National database of PPV reps that are available for specific projects”
- “What will change?”

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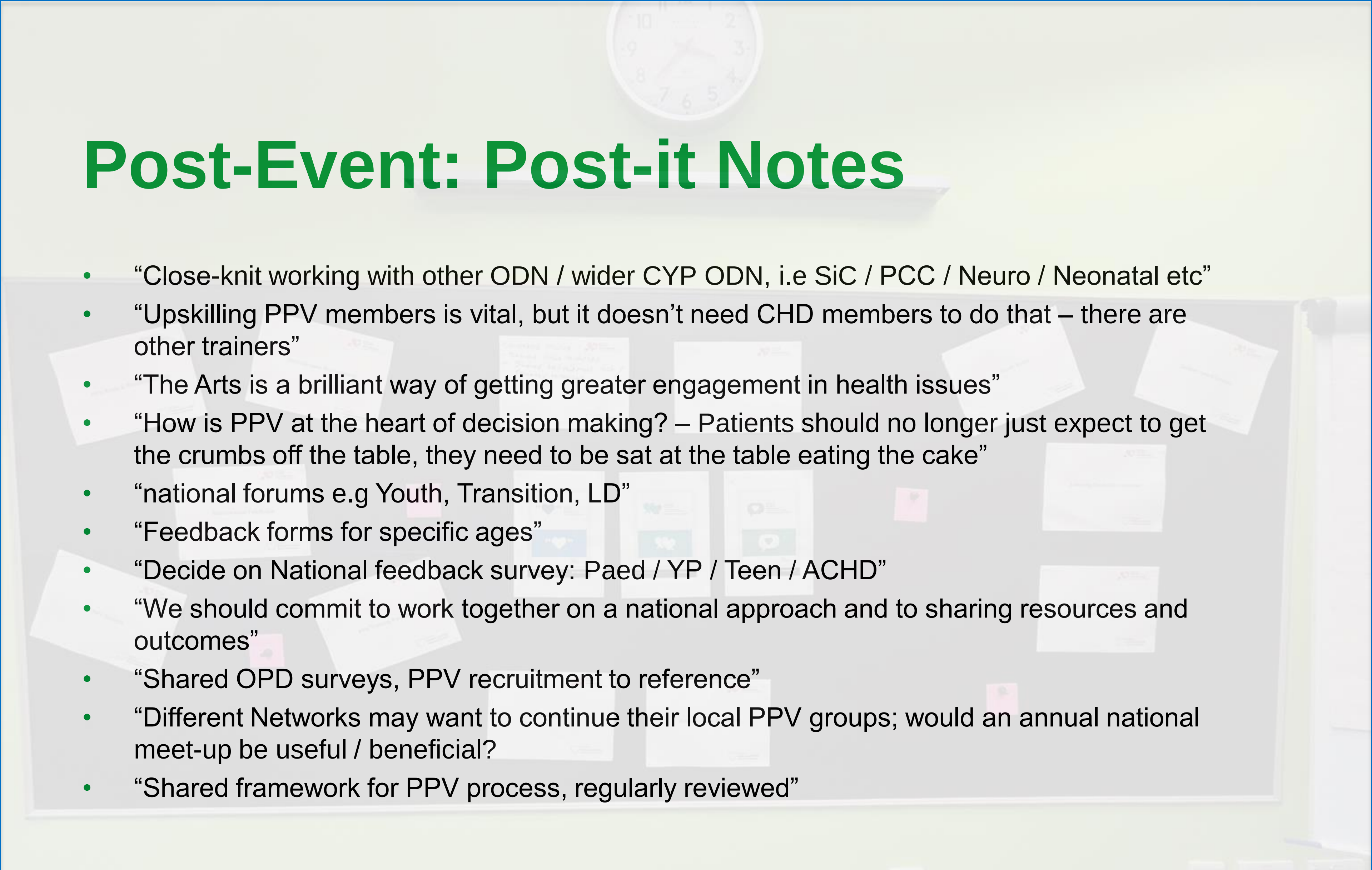

Post-Event: Post-it Notes

- “Close-knit working with other ODN / wider CYP ODN, i.e SiC / PCC / Neuro / Neonatal etc”
- “Upskilling PPV members is vital, but it doesn’t need CHD members to do that – there are other trainers”
- “The Arts is a brilliant way of getting greater engagement in health issues”
- “How is PPV at the heart of decision making? – Patients should no longer just expect to get the crumbs off the table, they need to be sat at the table eating the cake”
- “national forums e.g Youth, Transition, LD”
- “Feedback forms for specific ages”
- “Decide on National feedback survey: Paed / YP / Teen / ACHD”
- “We should commit to work together on a national approach and to sharing resources and outcomes”
- “Shared OPD surveys, PPV recruitment to reference”
- “Different Networks may want to continue their local PPV groups; would an annual national meet-up be useful / beneficial?
- “Shared framework for PPV process, regularly reviewed”

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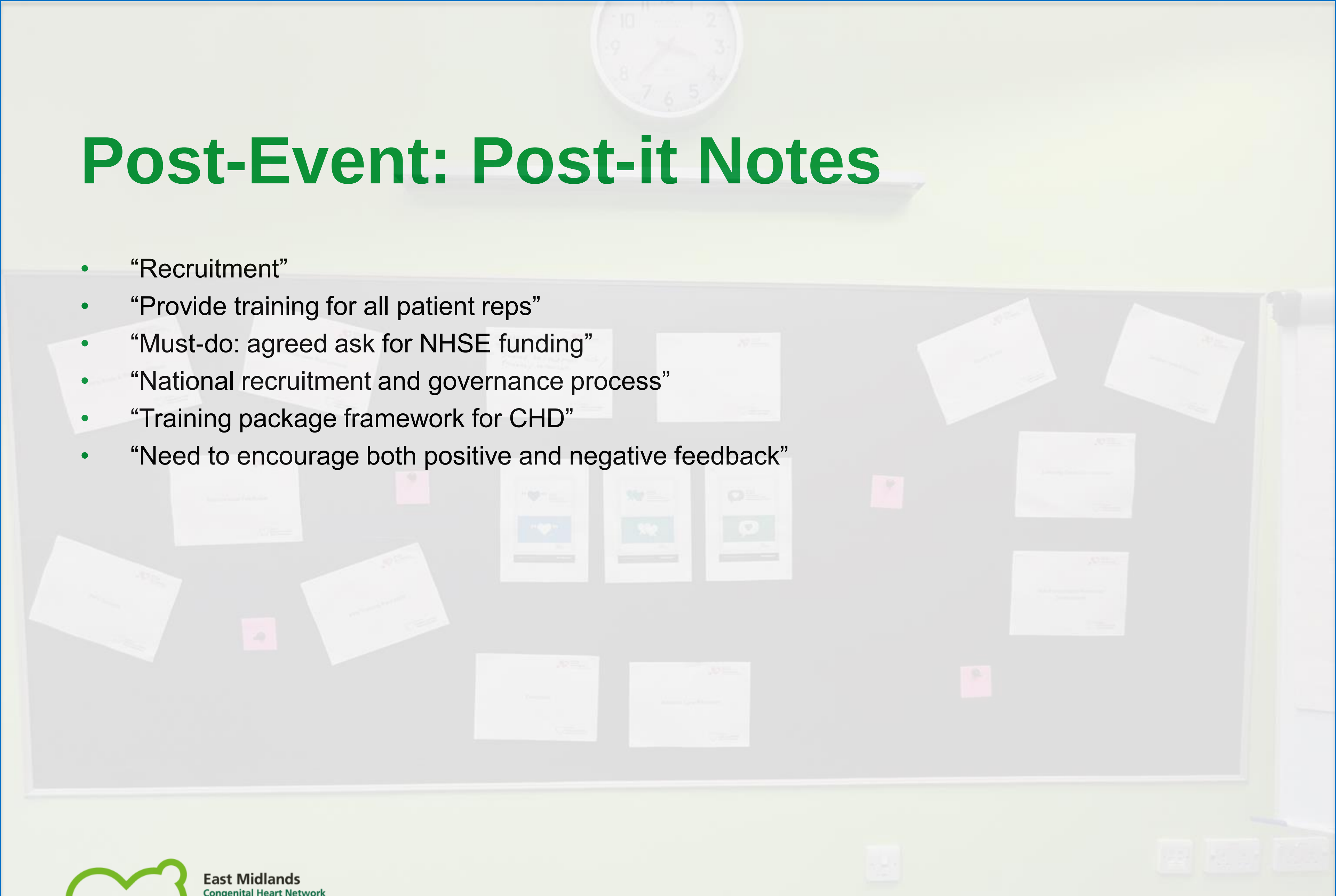

Post-Event: Post-it Notes

- “Recruitment”
- “Provide training for all patient reps”
- “Must-do: agreed ask for NHSE funding”
- “National recruitment and governance process”
- “Training package framework for CHD”
- “Need to encourage both positive and negative feedback”

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Post-Event: Table-Tops:

Service User Recruitment

How to Recruit?

- Coffee evenings
- Outpatients
- Charities

Going out into the community

- Religious groups
- WI
- Community groups of all kinds
- Students Union
- Hospital community
- GP Surgeries
- Health Centre's
- Find the hook
- National Heart charities
- Citizens Advice Bureaus

How? Different kinds of communication

- Posters (everywhere!)
- Videos
- Social media of all kinds
- Information stands
- Pull-up banners
- Hospital leaflets
- Charity magazines and websites
- Hospital newsletters
- Drop-in sessions via Teams / Zoom
- Event flyers

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Post-Event: Table-Tops:

Service User Feedback

Role of PPV: Vital to provide feedback and equal parity at the table; important to listen and to act

- Feedback questionnaires
- Capturing patient groups
- Facilitated Focus groups, led by patients
- Communications: Clinic letters, QR codes, Social media, Digital, Charities
- National: Agree basic / common questionnaires, include local data
- BAME: reach out to local organisations / council / charities
- LD: Keep it simple; don’t put barriers in the way

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Post-Event: Table-Tops:

Service User Feedback

Questionnaires: Proposals

- Don’t reinvent the wheel, adapt it
- Duplicate existing questionnaires and processes
- Inputs tailored to local needs
- Outputs accessible to Networks / Regions

Questionnaires: Hot questions

- Where you are told how to access
- Emotional support for your child
- Admission to DGH for heart palpitations; did the doctors communicate with the cardiac team?
- Have you ever experienced a delay in decisions being made?
- Did you have to repeat information several times to different staff?

Output

- Video: supporting children coming into hospital (psychology and play)
- Open access to Level 3 for identified vulnerable children

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Post-Event: Table-Tops:

PPV Roles & Responsibilities

What does a PPV Rep do?

- Patient voice (patient / parent / carer)
- Identify issues i.e. transition, psychology, research
- Identify hard-to-reach areas such as BAME, LD
- Education
- Service Feedback

What could we do?

- Advocacy training
- Train other PPV

Do you want to….

- Use your experience as a patient / parent / carer?
- Help improve care?
- Provide feedback on services?
- Help shape CHD care?
- Give something back?

…if "yes", would you like more information on becoming a member of our Patient / Parent / Carer group?

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Post-Event: Table-Tops:

Resource Development

Video

- Lived, common experiences
- Different conditions
- Mixture of patients and healthcare professionals
- Practical videos: use play specialists, physios etc
- Questions around Surgery, timeframes etc
- Good communicators to create confidence (patients and professionals)
- Transition: Patient & professional views
- Difficulties faced with the offer of hope: Shared experiences talking openly about feelings
- Info video for age groups to show to schools, for teachers & pupils. What can they do?
- Not just on website; YouTube, Tiktok, Instagram

Website

- Website specific to patients
- FAQs
- AI Chat bots
- Practical, informative guides
- Less jargon
- Less writing
- More interactive
- Video content
- Patient forum

“Make patients feel less alone”

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Post-Event: Table-Tops:

PPV Training Package: What to include

- Why it matters – the bigger picture
- Raising complaints
- Non-digital options
- Help with public speaking
- Understanding the data
- Facilitator training
- Emotional resilience
- Teams / Zoom training
- Jargon-busting & acronyms
- Recognition of participation
- Critical appraisal skills
- Literature review skills: understanding & education of CHD
- Data protection
- Safeguarding
- Conflict resolution
- Understanding the purpose of the PPV group
- Responsibilities of the group
- Appropriate communication options (WhatsApp etc)
- Appropriate signposting for further help
- Bitesize style training
- Mandatory and optional extras elements
- Understanding inequalities
- BAME
- Branding identity credibility
- Local Network welcome meeting – relevant current issues

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Post-Event: Table-Tops:

Palliative Care

- Embed Palliative care in lifelong pathway
- Include in conversation – How?
- Learning from Together for Short Lives and SANDS
- How to support / counsel families
- Difficult conversations – when do you talk about it?
- Daily support – siblings, friends & family
- Integral with hospice care service / hospice at home
- Symptom management
- Engage PPV in what terminology / language to use when speaking to patients
- Engagement with stakeholders e.g GP, primary care
- Acceptance of palliative care as valid pathway
- Advanced care planning: raising need / awareness
- Feedback at all levels
- Psychological support

“Talking about it”

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Post-Event: Key Actions

Development of Training Package

- Go to charities / NHSE re: offer
- Challenge NHSE re: training offer

Resource Development

- Key priority: Transition
- EMCHN to fund Transition video
- Collate national feedback to funded Transition video

Palliative Care

- How and when to engage PPV
- Normalise death / dying discussion
- Psychological support & signposting
- Consult Little Hearts Matter for guidance
- Clearly defined, appropriate terminology

Recruitment

- Communicate through multiple medias: charity newsletters, social media etc
- Make pathway recommendations
- Make as accessible as possible
- Shared learning from NW drop-in sessions

Survey

- Were you told how to access emotional support?
- L3 / DGH admission: did they communicate with specialist cardiac team? Were plans communicated? Were there decision making delays?
- **ACTION:** NW and EMCHN to draft survey proposal

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Post-Event: Key Actions

Roles & Responsibilities

- People who provide feedback
- Recruited roles
- **ACTION:** Glossary of Terms, in simplest possible format.

Next Meetings:

- **Virtual via Teams 3/12 (June/July '24)**
- **Face-to-face annually (March '25)**

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