Patient and Public Engagement (PPE)

PPE in Clinical Audit 2009
“I want to be part of the clinical audit process because I believe that my input can help make a difference which may benefit many people.”

Kate Wilkinson
Service user
Clinical audit must include patients. They, as well as clinicians, are the true professionals in illness. The doctor may be highly qualified to diagnose and give treatment. However, only the patients truly know the pain, physical and psychological, and the stress of their illness. The patient’s voice is so valuable as part of audit.

Iain Thomas
MINAP representative
Member of the SW London Cardiac and Stroke Network

ACKNOWLEDGEMENTS

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Part 1: Introduction

1.1 Healthcare Quality Improvement Partnership (HQIP)

HQIP is an organisation set up to re-invigorate clinical audit and improve quality in clinical care. It is a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing and National Voices.

National Voices is an umbrella organisation that brings together a broad and diverse coalition of voluntary sector organisations that represent patients, service users and carers.

HQIP is an alliance, with an unrivalled combination of professional and patient interests working together for quality, focused around quality improvement methods created and run by clinicians.

HQIP has several key aims in relation to patient involvement that are expressed in the way it works as an organisation and the models of clinical quality improvement it recommends. For example:

- Patients and professionals in the NHS need to work together to improve quality.
- Patients or their representatives should play a role in advising on the products or guidance it develops as an organisation.
- Patients need to be involved and engaged in the selection of initiatives to improve quality; in the governance of these initiatives, such as a clinical audit; in the collection of data for the audit; as part of the dissemination of the products to ensure, as consumers, they are provided with re-assurance and possible choice of healthcare provider, where such a choice is realistic or possible.

1.2 The HQIP Patient Network

The HQIP Patient Network was set up in early 2009. It identified, and therefore recommended, that guidance was needed to support patient engagement in clinical audit. They have been consulted throughout the development of this document via the use of two focus groups and several email consultations. They have identified much of the content of this work and have been involved in the writing up of the case studies and have been quoted throughout the document.

1.3 The purpose of this document

Patient and Public Engagement (PPE) has developed from grounding in services for people with mental health or substance misuse settings, now nearly all of healthcare understands the importance and value of PPE. This document seeks to interpret the principles of PPE specifically to clinical audit.

This guidance covers:

- **Why** patient and public engagement (PPE) is a legal requirement and also a genuine benefit to clinical audit;
- **How** to involve and engage patients, using recent standards and indicators published by the NHS Centre of Involvement (NCI) and integrating them with HQIP’s patient involvement criteria as detailed in Section 5 of the ‘Criteria and Indicators of Best Practice in Clinical Audit’ (2009) (Appendix 1); and
- **Examples of good practice in PPE** identified from an HQIP mapping project which identified a number of clinical audits that have practised effective PPE with successful outcomes. Five projects are therefore cited as case studies to illustrate good practice of PPE through the application of various methods such as patient surveys, patient panels and patient representation at all levels of an audit cycle.

1.4 Scope of the document

This guidance has been produced by HQIP to encourage and facilitate patient and public engagement in clinical audit. The document is:

- **Aimed** at those who run, manage, design or are involved in clinical audits, nationally, regionally or locally, whether managers, clinicians, or audit specialist support staff.
- **Focuses** on the engagement of patient and public representatives, including those who are currently receiving or have previously received care which has been subject to a clinical audit, or those who volunteer to participate in clinical audit practice.
- ** Covers** how information about clinical audit, including the results, should be communicated to patients and the public, to aid their information and their choice about services. An example of this is illustrated in case study 5.
- **Represents** the views of patients about how they want to be involved in, and informed about, clinical audit.

This guide will be complemented by other, more detailed material aimed at helping clinical audit managers improve the way they communicate their results to the general public who may be consumers of the healthcare being discussed; and by guidance for patients to help them understand clinical audit reports and results.

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1. PPE includes patients, carers, service users and the public and can also be referred to as patient and public involvement (PPI).
2. Please note that the NCI closed on 31st August 2009 at the completion of its contract with the Department of Health.
3. As part of the initial research HQIP contacted National Clinical Audit Patients Outcomes Programme (NCAPOP) leads and Local Audit leads and asked about PPE in their projects.
Part 2: Why involve patients in clinical audit?

2.1 Background to PPE
Internationally, PPE is increasingly seen to enhance all healthcare, including clinical audit, by being a marker of services that are oriented, planned and delivered towards patient interests. The involvement of patients provides a different perspective from that of clinicians. Within clinical audit it is a way of showing that what is being measured matters to patients.

The Department of Health (DH) has published a range of guidance and legislation to promote PPE within health and social care as a whole, and strives to ensure that it is incorporated into the way in which the NHS makes decisions and improves services. Key documents are highlighted in Appendix 2.

2.2 Models of involvement
Academic literature provides a theoretical and conceptual model of PPE. Historically, Sherry Arnstein’s ladder of participation has been used to describe the ways in which a patient/service user may wish to become involved, and illustrates what level of involvement an organisation has reached. (Appendix 3)

The ladder has been frequently adapted, but often the models show information – informing patients of the services available, expectations and the results of a clinical audit – as the lowest level of engagement.

Consultation is often mistaken as a high level of involvement but is commonly interpreted as merely sending out a survey, it is placed in the middle of the ladder and considered lower than actual engaging or partnering the patient.

The highest level of engagement is described as Partnership (as demonstrated in Arnstein’s ladder, 1969). This refers to working together to develop a clinical audit from the beginning, participating throughout the process and with potential for some audits being Patient-led, see case study 3. (Illustrated by Hanley et al, 2004).

These models of involvement are described in more detail in Appendix 3.

2.3 The benefits of PPE in clinical audit
Experts
Those who have lived with, or cared for, someone with a particular illness are “experts” in the condition; they have a subjective and most valid viewpoint based on actual experience about where quality could, and should, be improved. (See case study 1).

Different perspectives
Patients’ direct experience of care gives them a different point of view about ways to improve the quality of a service. Patients and clinicians will make different choices about the various elements of care which are reflected in standards and which are measured by a clinical audit and this can lead to improvements which are more responsive to patient needs.

“Current or recent NHS patients are likely to bring different perspectives to bear from those held by the general public. All these distinctions should be taken into account.”

Creating a desired service/a successful clinical audit more attuned to patient interest
By being involved within a PPE programme, patients can influence and participate in achieving services better focused on their needs. Through participation and engagement, a patient can enhance clinical audit by assisting in developing action plans which address the concerns they will have raised, thereby giving a clearer picture to the staff about what changes are needed within a service, and helping to ensure that services are being provided in the way people want to see. (See case study 3).

Informed choices
Clinical audit results can provide patients and the public with more knowledge about the quality of care in a particular healthcare setting, enabling them to make more informed choices, where this is possible, about where they obtain treatment. (See case study 5). As part of good PPE in clinical audit, the communication of audit results should be done in such a way that ensures it is accessible and understandable to the public, i.e written in a simple way with clearly understandable conclusions and data. Public reporting will raise public confidence in the NHS as it boosts trust and satisfaction; and PPE in clinical audit will give patients a deeper insight into care that is provided. Provider organisations should take care not to suppress clinical audit results that are negative or critical of care.

Many clinicians, and some managers, are concerned about audit data being used to inform patient choice. They may feel that the...
primary purpose of audit is internal review of compliance with clinical standards. Their concerns would be that audit data can be difficult to understand, and very often needs a degree of interpretation and context for the meaning to be clear. For example, straight like-for-like comparisons may be problematic as issues of case-mix may mask variation in clinical competence and lead to uninformed expressions of choice rather than informed ones. Also, some clinicians are unclear of how the ‘choice argument’ is applied.

HQIP shares and understands these arguments. Inevitably there must be a balance. In practice many patients neither want nor need to exercise choice; they want to be able to receive good services everywhere, and in this context choice is a diversion from the pursuit of universal high standards. Nonetheless patients have a right to see whether a unit or individual practitioner is competent, rather than just having to assume that they are. Those who participate in clinical audit should share their audit results, even if they need to have appropriate caveats in order to make accurate comparison.

Improving health
Strong social support networks are proven to benefit health and increased confidence and self esteem is directly related to health and well being\(^7\). Being involved in improving the quality of care can bring health benefits to patients through the satisfaction of having influenced their care, being listened to, and from the social interaction and engagement that this offers.

Engaging new people
Finding new people to comment or get involved in informing care is sometimes a struggle. LINks, for example, provide the connection that trusts need to access interested and enthusiastic patients and public who may want to be involved in clinical audit. (See case study 2) National organisations can do the same, for example the national clinical audit MINAP made links with patients through the British Heart Foundation. (See case study 1).

There may also be opportunities to reach out to people who want to comment and give their views, but who do not necessarily want to be extensively involved, for example through the use of electronic media. The various websites which exist to channel patients with a view about the care they receive, such as Patient Opinion (http://www.patientopinion.org.uk/), offer opportunities to widen the pool of persons who might become engaged.

Responsive to local needs
Communication with LINks, or other local patient forums and organisations, is a way of listening to local people and developing clinical audits that are responsive to local needs. Patients and public feel a greater ownership of local health services if they are consulted and listened to. Furthermore LINks can help access other people who are often ‘seldom heard’. This will contribute to a more cohesive local society\(^8\) and active citizenship.

Developing improved quality of care
Patients and service users have a legitimate role in determining what constitutes high quality and contributing ideas for improvement.\(^9\) PPE will give clinical audit insight into the preferences of patients as to suitable indicators of the quality of care provided. It will further assist in the identification of what is needed to maintain and improve care in the future.\(^10\)

A study using reviews between 1998-2006 was published evaluating the efficacy of patient-focused interventions. The evidence in this study suggested that carefully designed interventions can have positive effects on ‘patient’s knowledge and experience, health service utilisation, health behaviour and health status’\(^11\).

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\(^7\) Patient and public engagement in the new NHS, DH 1999
\(^8\) Tavistock and Portman, PPE Strategy, 2003
\(^9\) Closing the Gap through Clinical Communities, The Health Foundation, 2009
\(^10\) Tavistock and Portman, PPE Strategy, 2003
\(^11\) Effectiveness of strategies for informing, educating and involving patients: an overview of systematic reviews – Angela Coulter and Jo Ellins, Picker Institute Europe (2006).
When considering the quality of care from patients’ perspectives there are two main aspects: its effectiveness (outcome) and its humanity (experience). We all want to receive effective care in a humane way.

Traditionally the outcome of care, if measured at all, has been based on clinicians’ assessments. Given that most care aims to reduce patients’ symptoms and disability and improve their quality of life, it makes sense to ask patients directly. Recently, patient reported outcome measures (PROMs) have started to be used in audits. Indeed, their use has been mandatory in the NHS for patients undergoing one of four elective operations since April 2009. The National Elective Surgery PROMs Programme is a major initiative in England with potentially 250,000 patients involved. The use of PROMs is now being encouraged in all national clinical audits that consider the outcome of care. Involvement of patients in this way can complement clinicians’ reports of outcomes.

Patients’ experiences of the humanity of their care – such as dignity and respect, receiving the information requested, waiting times, cleanliness of facilities – are just as important as outcomes and can be collected from patients using questionnaires. Patient reported experience measures (PREMs) can be used to assess the degree to which the care offered and provided met criteria of good quality. As with any survey, questionnaires need to be reliable and valid. (See case study 4).
Part 4: Clinical audit

This section has been recommended through the patient/carer consultations and provides a brief summary and overview of what is clinical audit. Clinical audit staff will already have a greater understanding of the subject; however, this section also introduces a revised cycle with stages that have been drawn together from a very extensive series of consultations.

4.1 What is clinical audit?
Clinical audit is a quality improvement process that seeks to enhance the quality of patient care, outcomes and experience through measuring and improving the quality of clinical services against agreed standards. Good quality clinical audit should demonstrate that what is being measured is important to patients.

4.2 The clinical audit cycle
HQIP's 'Criteria and Indicators of Best Practice in Clinical Audit', published in September 2009, was compiled after extensive consultation with clinical staff, patients and audit professionals, and represents the 'gold standard' that can be applied to a good clinical audit project or process. It highlights four main stages of the clinical audit cycle as follows:

- **Stage 1: Preparation and planning (including for re-audit)**
  - Organisational arrangements
  - Stakeholder engagement
  - Patient engagement

- **Stage 2: Measuring performance**
  - Clinical audit methodology
  - Data collection process
  - Data analysis and reporting

- **Stage 3: Implementing change**
  - Action plan development (including action to take forward recommendations made)

- **Stage 4: Achieving and sustaining improvement (including re-audit where necessary)**
  - Re-audit
  - Continuous improvement.

This framework identifies patients and carers as key stakeholders in the clinical audit process, and recommends 'that if appropriate and feasible, patients, patient representatives and relevant patient organisations, should be involved at all stages of the audit cycle as equal members of the audit team'.

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1. Criteria and indicators of best practice in clinical audit, HQIP, 2009
Part 5: How to involve and engage patients and the public in clinical audit

HQIP’s ‘Criteria and Indicators of Best Practice in Clinical Audit’, section 5, (Appendix 1) refers to patient representation and participation as a key element in achieving good quality clinical audit.

The suggestions for how to involve patients (and carers as appropriate) are anchored around the NHS Centre for Involvement’s (NCI) set of six organisational standards, (Appendix 4) that identify what NHS organisations need to do, to ensure meaningful PPE in clinical practice.

This framework can be used as a helpful structure to support and aid PPE in clinical audit with suggestions given to how the standards may be achieved. HQIP have adapted the standards and included additional criteria in order to give more in depth guidance for specific engagement in clinical audit.

**STANDARD 1:**

**People:** Roles and responsibilities for PPE are clearly defined, visible and effective throughout the organisation including leadership at all levels.

*Patients involved in clinical audit need to know what their role is and what they are being asked to do; this needs to be widely understood and agreed, or patient engagement will be tokenistic and unfocused and patients will not feel valued and their skills and experience utilised effectively.*

**CRITERIA:**

PPE in an organisation is managed and led. Staff and clinicians who lead clinical audit projects are trained and informed about the benefits of PPE. Systems and policies are in place, and steps taken to engage patients and carers in clinical audit.

Patients who are members of a clinical audit management or delivery team are fully informed about what is expected from them in terms of participation, commitment and workload.

The patient group to whom the clinical audit standards apply is clearly defined.

If required, patients who are members of the clinical audit team are given basic training to enable them to contribute effectively to the process.

**HOW?**

- The organisation has named individuals responsible for defined PPE in clinical audit.

- All staff and volunteers within an organisation, or working on clinical audit, know their responsibility for PPE.

- Patients and carers with formal PPE links to the organisation have clearly defined role descriptions covering the scope of their engagement in clinical audit.
• There are policies in place to support PPE activity including:
  • a reimbursement policy
  • a reward and recognition policy
  • a communications policy
  • a policy on information governance related to patient engagement
  • a policy or policies outlining governance arrangements for PPE
  • a policy or policies that outline health and safety arrangements for PPE
  • a policy on support available to involved users.

• There is a training programme in place to support PPE including:
  • inclusion of PPE in induction training of staff
  • inclusion of need to involve patients
  • training of patients and public volunteers.

STANDARD 2:

PPE strategy and vision: There is an explicit strategic framework that makes clear the organisation’s commitment to PPE.

The rationale and purpose behind PPE needs to be understood by those responsible for management; its value needs to be shared by those with responsibility. This shared vision needs to be expressed within a strategic framework.

CRITERIA:

PPE is owned at board or senior management level.

There is an explicit link between the organisation’s clinical audit strategy and its PPE strategy.

HOW?

• There is a publicly available document, approved by the board or management group that sets out the organisation’s vision for PPE, and that this covers clinical audit.

• The organisation has a defined set of objectives for PPE activity, which covers clinical audit.
STANDARD 3:

PPE structures: Structures are in place at all levels of the organisation that facilitate dialogue and communication with patients, carers, the wider community and the public.

Strong efforts need to be made to ensure the patient is engaged systematically, especially in communication or dissemination strategies.

CRITERIA:

Patients are kept informed and supported throughout the clinical audit process about timescales, progress, results and actions.

All communication should use simplicity of language and avoid the use of jargon and acronyms.

HOW?

• An organisation’s clinical audit programme, and the results, are pro-actively communicated to patients and public via appropriate communication channels, for example mailings, meetings, LINks groups, ward notice boards, websites, newsletters or local media. This should include clinical audit results which are critical as well as audit results which are positive.

• The value and potential impact of any national or local clinical audit is effectively communicated to patients who will be directly affected. A greater understanding of the process and what their role is within it is more likely to increase patient’s and carer’s support.

• Progress updates and clinical audit results are shared with patients in an accessible format – too much clinical audit data is difficult to understand, by clinicians, managers and patients alike. Efforts should be made to communicate this more easily. HQIP will issue guidance on this in 2010.

• National clinical audits should be proactive in assisting local provider organisations and PCTs with their patient communications by supplying relevant clinical audit data and results as required. National clinical audits must make every effort to ensure their data are useable; helps prompt change, and is timely, in respect of patient interests.
STANDARD 4: PPE processes:

Processes are in place at all levels of the organisation that enable patients, carers, the wider community and the public to effectively influence the planning, delivery, development, review and decision-making about changing and improving healthcare services.

Patient engagement needs to be integral to an organisation. Such engagement needs to have direct impact at all levels in an organisation and in relation to such processes as clinical audit, at an early stage.

CRITERIA:

The organisation takes steps to ensure PPE in the setting of clinical audit priorities and in the development of the annual clinical audit programme.

Patients are involved in helping to plan and enact changes arising from clinical audit, and to monitor results.

Where the public is part of the clinical audit team, systems must be in place so that there is no breach in Caldicott guidelines\(^1\) i.e. access to other patient data must be restricted.

Clinical audit standards take full account of patient priorities and patient-defined outcomes. Where possible the audit incorporates PROMs (See part 3).

HOW?

- The local organisation or national clinical audit is able to demonstrate that it evaluates both the experience and outcomes of PPE activity and their impact on staff, patients and the public.

- Results of the clinical audit, and action plans are openly shared and communicated with patients and the public.

- Patients are involved in both the conduct of clinical audits and their governance.

- Patient groups are advised of the healthcare organisation’s clinical audit programme and supplied with results on a routine basis.

- Quality Accounts should show organisational participation in clinical audit and how patients have been involved.

- Patients are involved in standard selection for clinical audit or were involved in the development of national standards which are used; any national standards set should be reviewed for their relevance to patient interests and added to as necessary with validated patient relevant standards. For example the NICE standards are developed with extensive patient involvement.\(^2\)

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\(^2\) http://www.nice.org.uk/getinvolved/patientandpublicinvolvement/patient_and_public_involvement.jsp
STANDARD 5:

Partnership working: The organisation has clearly defined structures and processes in place that enable effective dialogue with partner organisations at national, local and regional levels.

CRITERIA:

Patients/carers are recognised as key stakeholders in the clinical audit process and, if appropriate, patient representatives and relevant patient organisations are involved in all stages of the clinical audit cycle as equal members of the clinical audit team.

HOW?

- The organisation has defined pathways mapping how it works with relevant patient groups and other health and social care partners including:
  - LINks
  - voluntary and community organisations at the local or national level
  - disease/condition specific interest groups, locally and nationally
  - hard-to reach and ‘seldom heard’ individuals, groups or communities
  - overview and scrutiny committees
  - Strategic Health Authorities
  - other health care organisations
  - social care providers
  - advocacy and support agencies and organisations
  - independent organisations.

- Patients who may be affected by changes in practice from clinical audits of services they use should be consulted, advised and involved in those audits.

- Patients should be encouraged to request clinical audit results.

- Carers and other relatives need to be involved in clinical audits where the patient cannot contribute fully, alongside the patient.

- Informal and ad-hoc systems of engaging the public in clinical audit and other PPE processes, such as online capture, can have a role in any engagement strategy.
STANDARD 6:

PPE monitoring and evaluation of effectiveness:
Systems are in place that monitor PPE activity and evaluate effectiveness and impact and which influence future PPE planning.

It is very easy to assume PPE is worth doing, and that the very existence of engagement processes are enough; however they need to be constantly reviewed in respect of their effectiveness and value.

CRITERIA:
PPE activity needs to be monitored, evaluated and reported.

HOW?

• The organisation accurately maps and records all PPE activity on a continuous basis, and this is reported and managed at board/senior management level.

• PPE is fully documented in all clinical audit reports.

Summary

Involvement and engagement of patients in clinical audit is vital and is a marker of high quality audit.

In essence, the engagement of patients and public, both nationally and locally in clinical audit needs to involve:

• Engagement in governance and strategic direction of clinical audit.

• Consultation in respect of standards (and outcomes, where appropriate) to be audited.

• Active participation in collection and analysis of clinical audit data.

• Engaging the public in communication activity about clinical audit, partly as patients or potential patients of treatment, and also through involvement in governance.

To achieve this, patient engagement needs to be part of the whole conception of the clinical audit, from beginning to end. It needs to be integrally part of the fabric of the whole project.

The information in this guidance is open to adaptation and is not meant as absolute instructions. They are suggestions that we hope will provide organisations with enough information to ensure there is PPE within their own clinical audits.

HQIP will continue to develop and publish further guidance on various aspects of patient engagement. These will be posted on the HQIP website.

There are some case studies in this guidance demonstrating innovative approaches to patient involvement, both nationally and locally, more will be added over time and will be posted on the website.

www.hqip.org.uk
Case studies

1. MINAP
2. CAPP
3. Mental health audit
4. PEG
5. Heart surgery in the UK
Case study 1:
MINAP – Myocardial Ischaemia National Audit Project

PATIENT PARTNERSHIP

This case study is an example of a national audit project that has patients and carers on the steering committee. The patients are experienced and are therefore respected as the experts on heart conditions. They contribute significantly to the project; their views are valued and supported; this knowledge encourages their input.

MINAP was initially established to allow hospitals to demonstrate their performance against standards for heart attacks in the National Service Framework for Coronary Heart Disease published in 2000. Those standards include the time it takes from the onset of heart attack symptoms until appropriate treatment is received; and the use of secondary prevention medication on hospital discharge to reduce the risk of another heart attack.

MINAP’s scope has subsequently been extended to allow hospitals and ambulance services to assess the management of all acute coronary syndromes.

MINAP has demonstrated that in 2008, 82% of patients in England received clot-busting treatment (thrombolysis) for heart attacks within 30 minutes of arrival at hospital, compared with 44% in 2002.

The MINAP public report was first published in 2001 and was the first national audit to produce a report for patients and the public showing how hospitals performed against the national standards for heart attack. MINAP has 100% participation rate from hospitals in England and Wales.

The MINAP steering group oversees the direction of the project and includes representation from all relevant stakeholders, including the Royal College of Physicians (RCP), The British Heart Foundation (BHF) and Cardiac Networks. It also includes two patient representatives from the MINAP Patient/Carer group. Professor Roger Boyle CBE, National Director for Heart Disease and Stroke, and Professor Peter Weissberg, Medical Director of the BHF, are among the members.

Professor Boyle comments on MINAP:

"The Project is almost certainly the largest and most comprehensive database anywhere in the world. The data continues to show year on year progressive improvement in processes and outcomes."

One patient/carer member (Iain Thomas) underlines the improvements:

"If MINAP were a new drug it would be hailed as a life-saver. That’s exactly what it is doing, helping to save the lives of heart attack patients by encouraging hospitals and ambulance trusts to improve performances."

Patient/carer group

The MINAP steering group identified the need to involve patients in the publication of the first MINAP Public Report, to ensure that the content and format would meet the requirements of patients and the public. The MINAP patient/carer group consists of two patients, a carer, members of the MINAP team, a representative from a hospital Patient Liaison Service, a BHF representative and the RCP Public Relations manager.

Cardiac Networks (CN) are established groups that are attached to most local hospitals with very active patients. The BHF have a close link with Cardiac Networks and the three patient/carer representatives of MINAP were found in this way. They all continue to be closely involved with and support the work of both the Cardiac Networks and the BHF. Both patients are well informed with a plethora of experience dating back several years, and are still involved in grass root PPI contact and activities. It has been a successful team, both due to the knowledge and experience of the patients involved and also because they have been accepted as equal partners. The patient/carer group are able to consider issues prior to full meetings so the patients are able to attend prepared.

The patient representatives on the MINAP steering group have an important role to ensure that patients have an input into the strategic direction of MINAP and especially in the future development of Patient Reported Outcome Measures.

MINAP delivers regional roadshows to promote the use of the data to improve patient care and the patient representatives participate, encouraging involvement from another perspective.
Effectiveness

- The patients bring a patient centred focus to the Board meetings.
- Patients are able to ask questions and make comment about sensitive issues and clinical shortcomings that others might be hesitant to tackle.
- Patients ask the questions that matter to patients.
- The three representatives have experience and up-to-date grassroots contacts.
- Patients are also able to extend praise and congratulations for jobs well done, where colleagues may be over reticent.

Funding for MINAP passed from the Healthcare Commission to the Healthcare Quality Improvement Partnership (HQIP) from April 1st, 2008.

MINAP was based in the Clinical Effectiveness and Evaluation Unit of the Royal College of Physicians (RCP) but relocated in 2006 to the National Institute for Clinical Outcomes Research at University College, London. It continues close collaboration with the RCP.

For more information please follow this link;
http://www.rcplondon.ac.uk/CLINICAL-STANDARDS/ORGANISATION/PARTNERSHIP/Pages/MINAP-.aspx

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“The patient’s voice is so important but do not forget the carer. There are about six million voluntary carers, relatives and friends of all ages, in the UK. They have more experience than a doctor of a patient’s pain, problems and care needs. They are the unrecognised figures in dealing with patients, their views should be brought into the open through audit.”

Sirkka Thomas
Former Health Visitor and Cardiac Nurse, now carer for her husband.
Case study 2:
CAPP – Clinical Audit Patient Panel

PATIENT PARTICIPATION

This case study is an example of patients and public choosing to become involved in general clinical audits within an organisation. The group volunteers to participate in the constructing, developing and collecting of data for a clinical audit. By being actively involved from the beginning, the patients/public are able to choose audit topics that matter to them and can contribute as necessary to ensure objectivity and validity.

The Commission for Health Improvement review in 2003 had highlighted that Sheffield South West PCT had a lack of patient involvement in their audit programme and, after hearing about a panel created in North Bristol Hospital, CAPP was established and has been operating since 2004.

The Clinical Audit Patient Panel consisted of 10 members who had been recruited after responding to a poster campaign encouraging involvement and asking for patients to volunteer and “make a difference”. Two of the original members had been previously involved within the services, and had experience of volunteering within the NHS but others had responded after seeing the posters and flyers in their community. After completing an application form, the group attended an information and training day and CAPP was established.

“I was interested because my husband was in hospital at the time with a serious illness.....and both he and I had to take early retirement, so CAPP offered an opportunity to get involved in health care issues.” – Mary Dalgleish, CAPP Member

The training session is a way for the volunteers to learn more about clinical audit and whether CAPP is what they want to be part of. It is also an opportunity for the audit team to assess the suitability of potential members. CAPP members do not receive any financial payment for volunteering but their expenses are reimbursed in line with the Department of Health guidelines.

“Volunteers join the PCT volunteering team by completing a short form and attending an informal discussion, where they are asked to complete confidentiality and equal opportunities forms. At that point they are asked what areas of interest they have and, if they have ticked the “Clinical Audit” box, the clinical audit team will contact them.”

– Helen Mulholland, Expert Patients Programme and Volunteer Manager – NHS Sheffield

The CAPP are now managed by the Clinical Audit and Effectiveness team within the Standards and Engagement Directorate at NHS Sheffield, but they are also part of the wider volunteering network managed by the Volunteer Manager. This not only ensures a co-ordinated approach to recruitment but also means patients are offered the opportunity to participate in other related projects and initiatives.

There are currently five members on CAPP with a further two awaiting training. An Equality Impact Assessment (EIA) was completed in 2008 focusing on the overall diversity of membership of the panel. An action plan was subsequently produced and agreed and the CAPP chair has recently been promoting involvement by attending the Provider Services Governance meetings. A new round of recruitment has been initiated across the city. New posters and leaflets have been designed and distributed for this campaign and are initially being displayed within GP and dental practices. (Appendix 5)

The CAPP chair attends NHS Sheffield’s Evidence Based Practice Group, where clinical audits are discussed and a variety of regular updates are presented, for example NICE, Medicines Management, research and the latest published evidence. This group are also part of the process whereby the clinical audit programmes are agreed and clinical policies are approved prior to ratification at Trust Board.

“The essence of CAPP is that they are directly involved with clinical audit projects and do not just sit on high level committees or organisational groups as token members. The panel are very much ‘hands on’ and this is what makes the significant difference between this panel and other patient panels in acute organisations.” – Beverly Ryton, Senior Clinical Audit and Effectiveness Facilitator

Patients are involved in every stage of relevant clinical audits, adding value to every aspect of the cycle. The following is a list of project examples that CAPP have been involved in:
• Record Keeping Audits (including dietetics, continence, district nursing, tissue viability).

• Funded Nursing Care Audit.

• Older People NSF – Standard 1: Age Discrimination. A CAPP member was part of the Standards group developing criteria for the audit of citywide policies in relation to age discrimination.

• NHS Live Audit – People with Breathing Difficulties (2005-6). The project methodology style is through the Discovery Interview technique, where each patient gives consent to be visited by a healthcare professional and a member of CAPP.

• Patient Satisfaction Surveys.

CAPP continues to be involved with the following:

• reviewing patient information/leaflets etc.

• reviewing questionnaires that will be used to elicit patient feedback for specific services

• dignity and respect – both on the steering group and devising the clinical audits

• Cardiac rehabilitation audit.

Currently CAPP are working with other volunteers on a project looking at Patient and Public Involvement (PPI) within NHS Sheffield. Looking at the impact of involving service users/patients/carers and the effect this has had on a service.

After some initial input from the PPI team, CAPP and the volunteers are now in total control of this project agreeing roles and responsibilities and what needs to be done, by whom.

Other work / involvement:

• Evidence Based Practice Group – CAPP are represented at the evidence based practice group by their chair.

• Conferences / Events – CAPP attend a number of national and local conferences, events and meetings to share their experiences and raise issues for discussion.

Why are CAPP effective?

CAPP members bring a lay perspective to clinical issues which have enabled them to reduce jargon and improve usability of materials designed for patients or the general public, and identify basic questions about key service issues. Because they are not employed by the service providers or commissioners, they can provide an independent sounding board for both patients and staff.

There is a comprehensive recruitment process in place, supported by NHS Sheffield.

Brian E Hodges
CAPP Chair
Email: brianE Hodges@aol.com

Beverly Ryton
Senior Clinical Audit and Effectiveness Facilitator
Clinical Audit and Effectiveness
NHS Sheffield
Email: beverly.ryton@sheffieldpct.nhs.uk
Case study 3: Mental Health Audit
Kent and Medway Care Program Approach (CPA) Service User and Care Audit

PATIENT LED PROJECT

This case study is an example of patients/service users and carers leading on a clinical audit from the development of the standards used to the data collection and to the development of the ensuing action plan.

This project was commissioned by the Kent CPA Audit Group in 2002 from US in Kent (a county wide service user and carer network). Clinical audit training was provided by local clinical audit staff to the CPA Service User and Carer Audit Group, which consisted of service users and carers from US in Kent in order to undertake the project.

Standards for the audit were developed by a group consisting of both service users and carers from their experience of the CPA process. The standards were an expression of what service users and carers expect the CPA process to deliver for them. The final standards for the project were agreed with the service users in Kent group. An audit questionnaire was developed and sent out to members of US in Kent group for their comments. A final draft of the questionnaire was agreed by the audit group.

A number of service user and carer interviewers were recruited to help respondents complete the questionnaire. All interviewers were provided with training, given an East Kent Clinical Audit Service Certificate and an identity badge to confirm their involvement in the project. Interviewers were encouraged to visit day centres, drop-in centres and conferences where service users and carers attended. All Mental Health Forums were also sent questionnaires and the questionnaire was also made available via the website (www.Kent.us.com). The audit group set a target of 250 completed questionnaires and a multi-media campaign to make Kent aware of the audit's existence was also undertaken.

Guidelines were given to the interviewers who in turn gave an information sheet and an informed consent form to the interviewees. These were developed and used to ensure that interviewees gave their informed consent to participate in the audit. Data analysis from the completed questionnaires was carried out by the East Kent Clinical Audit Service.

The audit group discussed the audit results and agreed to communicate the results to key mental health and social services managers within Kent and Medway at a stakeholder day. An action plan was drafted and communicated to all stakeholders.

1 Clinical Audit and Effectiveness Service User and Carer Involvement Strategy, 2009-2012 – Kent and Medway NHS and Social Care Partnership Trust.
Case study 4: PEG – Percutaneous Enterogastrostomy Tube

PATIENT SURVEY

This case study shows an example of a Patient Survey, which carried out an analysis before formulating the questionnaire to ensure the survey covered the themes that mattered to the patients. The survey had a high participation rate and the results gave rise to action and change.

The Royal Surrey County Hospital NHS Trust, encouraged by recent policies and due to increase in the number of complaints from these patients, carried out a Percutaneous Enterogastrostomy tube (PEG) audit.

The aim of the project was to improve the experiences of patients who have a PEG inserted. These patients have a tube inserted either surgically or endoscopically, most often due to head and neck cancer. All patients are referred to Karen, the nutritional support nurse, who is one of a team that provides the essential care both pre and post insertion, including follow up at home.

A multi-method approach was used to capture the most valid and reliable information to carry out the study. This involved two stages; initially an unstructured interview was performed with a random selection of five patients (at a location of their choice) who had a PEG in situ for at least three months. The interview was arranged by sending a letter, and was subsequently performed by Karen, tape recorded, and analysed by the audit department.

The core aim of this interview was to retrieve patients views and experiences of the PEG pathway, and from a qualitative analysis technique known as ‘thematic analysis’, generate core themes of this pathway that mattered to patients. It would also be used as the basis for questions in the survey to be sent by post to all patients who had a PEG inserted between 2004-06, and had it in situ for three months.

The final questionnaire

A questionnaire was a series of semi structured questions, and was sent out with a cover letter. It was subjected to a pilot phase, where a further five randomly selected patients were asked to comment on its ease of completion, flow, comprehensiveness (in terms of question coverage) and graphical layout. The responses to this resulted in a final questionnaire for which to begin the survey.

To encourage a good response rate, two reminders were sent to non-responding patients within three and six weeks of the original questionnaire being sent.

Over the two years, 69 patients were identified as being eligible for the audit. Of these, an impressive 72% returned the questionnaire. It has been claimed that the two reminder system is able to retrieve 50% of the entire response rate.

The results showed many areas of excellent practice. This included:

- whether the patients felt it was the right decision to have a PEG.
- MDT involvement prior to insertion and their level of helpfulness.
- the amount and clarity of information given to prepare the patient for PEG insertion and its adequacy in preparing them for the procedure.
- whether information was given about the administration of feeds and whether this was of sufficient quality to enable them to feel confident to administer the feeds.
- overall ease of looking after the PEG site; and
- whether they were followed up, and the quality of such, once discharged.

Results and reflections

The audit also found that a significant number of patients were not comfortable with their body image. The nutrition support nurse now spends a much greater proportion of her time talking to patients and will refer to psychological services if she anticipates any problems with acceptance.

In terms of weight, a significant proportion of patients described themselves as having an alteration in weight and in fact losing weight. Karen has now spoken to the Dietetic department, and they are performing their own in-depth audit into whether these
particular patients are complying with their recommendations around feeds.

Upon reflection some of the negative aspects of this audit include the significant resources that were needed to complete the project, making it hard to re-audit and that in hindsight some of the results may have been biased as a result of a member of the team carrying out the interviews.

Work that has yet to be done since the audit include feeding back to the original participants on actions taken, and the need to develop numerical patient based standards from the core themes identified.

From a positive point of view, RSCH NHS has carried out an audit that examined topics that mattered to patients, and as a result of this we have taken actions and some, if not all have been implemented.

Helen Brady
Audit and Service Improvement Manager
The Royal Surrey County Hospital NHS Trust
Guildford
e-mail: hbrady@royalsurrey.nhs.uk

Case study 5: Heart Surgery in the UK
Care Quality Commission (CQC) and The Society for Cardiothoracic Surgery in Great Britain and Ireland (SCTS)

PATIENT CHOICE

This case study is an example of clinical audit results being communicated to the public in a way that is understood and clear for a potential patient, giving the public the ability to make informed choices about where and by whom they would prefer to be operated.

Through specific, agreed resources data are collected, aggregated and validated. The information is then analysed and continuously evaluated illustrating the performance of surgeons from 55 hospitals and all the NHS hospitals undertaking adult cardiac surgery.

With the Care Quality Commission (CQC) the SCTS have developed a website that illustrates survival rates and important information on different types of heart surgery for each surgical unit within the UK. The development team also included groups of patients from the British Heart Foundation, the Greater Manchester and Cheshire cardiac network and representatives from Heart Care Partnership UK.

The website is accessible and easy to use, by clicking on a map of the UK it links through to a specific hospital and all their statistics and details. For example for John Radcliffe Hospital in Oxford:

- Total adult cases for the year ending March 2007: 783
- No. surgeons who undertake adult heart surgery: 5
- No. consultant anaesthetists with any adult heart surgical practice: 10

The page also shows the survival rate and allows for comparison with other surgical units in the country.

Below is a screen shot illustrating the list of surgeons and the number of times that they perform an aortic valve replacement operation in this unit.

There is a specific ‘Information for Patients’ page, with clear instructions demonstrating how to read the diagrams and interpret the information.

The Sixth National Adult Cardiac Surgical Database Report, 2008 – Demonstrating quality, is also now available and more information can be found on http://www.scts.org/
Appendices

Appendix 1 – Criteria and indicators of best practice in clinical audit

Appendix 2 – Guidance and legislation for patient/public engagement

Appendix 3 – Models of involvement

Appendix 4 – Organisational standards

Appendix 5 – CAPP’s promotional poster
Appendix 1:
Section 5 – Criteria and indicators of best practice in clinical audit

<table>
<thead>
<tr>
<th></th>
<th>Patients or their representatives are involved in the clinical audit if appropriate.</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>5.1</td>
<td>The patient group to whom the clinical audit standards apply is clearly defined.</td>
<td></td>
</tr>
<tr>
<td>5.2</td>
<td>The clinical audit standards take full account of patient priorities and patient-defined outcomes.</td>
<td>For example, the clinical audit incorporates Patient Related Outcome Measures (PROMS).</td>
</tr>
<tr>
<td>5.3</td>
<td>Patients/carers are recognised as key stakeholders in the clinical audit process.</td>
<td>If appropriate and feasible, patient representatives and relevant patient organisations are involved in clinical audit governance, treated as stakeholders, and where appropriate, in all stages of the clinical audit cycle as equal members of the clinical audit team.</td>
</tr>
<tr>
<td>5.4</td>
<td>Patients who are members of the clinical audit team are fully informed about what is expected from them in terms of participation, commitment and workload.</td>
<td>Not all patients and/or patient organisations will be members of the clinical audit team but, as relevant stakeholders, should still be kept informed and engaged.</td>
</tr>
<tr>
<td>5.5</td>
<td>If required, patients who are members of the clinical audit team are given basic clinical audit training to enable them to contribute effectively to the clinical audit process.</td>
<td></td>
</tr>
<tr>
<td>5.6</td>
<td>Patients are kept informed throughout the clinical audit process about timescales, progress, results and actions.</td>
<td>All communications should use plain English avoiding the use of jargon and acronyms.</td>
</tr>
</tbody>
</table>

1 HQIP, 2009
Appendix 2:
Guidance and legislation for patient/public engagement

**Patient and public involvement in the new NHS, 1999**
This document made it clear that a better understanding of how services should be developed could only be gained by involving the local community.

**Patient and Public Involvement Forums (PPIFs), 2003**
Following guidance set out in the NHS Reform and Health Care Professions Act 2002, Patients’ Forums were set up to improve the quality of NHS services by representing to trusts the views and experiences of patients, their carers and families. Superseding Community Health Councils, PPIFs were established as independent statutory bodies for all NHS trusts and PCTs in England, to monitor and review the range and operation of services both provided and commissioned. In 2008 PPIFs were disbanded and have since been replaced by Local Involvement Networks (LINks) – (see section below).

**NHS Act, 2006**
The NHS Act 2006, section 242, stated that all NHS organisations had a “Duty to Involve” by ensuring that arrangements were in place to involve and consult in planning service provision, the development and review of changes in service provision, and decisions affecting service operation.

**Health and Social Care Act, 2007 and Local Involvement Networks (LINks)**
The Health and Social Care Act (2007) reiterated that PPE should be part of the “core business” of every NHS organisation and replaced PPIFs with LINks. Each local authority has government funding to enable LINks activities to take place from 2008 – 2012. LINks are independently run by agencies or charitable groups with the aim of giving local citizens a voice and the authority to monitor local services and hold providers to account.

**High Quality Care for All: NHS Next Stage Review, 2008**
Lord Darzi’s report emphasised the need for high quality care for patients and the public and the need to work in partnership. By stating that “measuring and valuing what matters most to patients, the public and staff is the way for NHS to make progress to quality care” the ‘duty to involve’ was further embedded as a key factor in ensuring the provision of quality services.

**World Class Commissioning and the NHS Constitution, 2009**
World Class Commissioning competencies include the promotion and continuous improvement of quality, emphasising, in competency three, that this should mean to;

“**proactively seek and build continuous and meaningful engagement with the public and patients to shape and improve health.**”

PCTs are responsible through the commissioning process for investing public funds on behalf of their patients and communities. In order to make commissioning decisions that reflect the needs, priorities and aspirations of the local population, PCTs will have to engage the public in a variety of ways, openly and honestly. They will need to be proactive in seeking out the views and experiences of the public, patients, their carers and other stakeholders, especially those least able to act as advocates. The NHS constitution, published in January 2009, also pledged to ensure that the public are fully informed and involved.
Appendix 3: Models of involvement

Arnstein’s Ladder

Sherry Arnstein developed her ladder of involvement in 1969 which shows an elevating framework of “Citizen Participation”, each rung representing a different level of involvement from total disempowerment to absolute citizen control.

Arnstein’s ladder can be a useful visual tool to gage the level of PPE currently within an organisation showing the various levels, including where patients/citizens do not participate at all and as merely degrees of tokenism.

8. Citizen control
7. Delegated power
6. Partnership
5. Placation
4. Consultation
3. Informing
2. Therapy
1. Manipulation

Figure 1. Arnstein’s Ladder, 1969

Adaptations of the ladder

Arnstein’s ladder has since been adapted many times; Health Canada’s complex looking public involvement continuum (Figure 2) illustrates five levels of involvement with the highest level shown as Partnership.

Other adaptations are often found within the drug and alcohol and mental health sectors, both increasingly recognising that service users are crucial components in the delivery of effective services. Arnstein’s ladder adapted by Susan Lawrence (Figure 3) has more emphasis on the service user choice, stating that it may be dependent on the organisation/service that they are involved with, for example an in-house detoxification centre compared to a drop-in centre. This adaptation has seven rungs referring to contribution, representation and implementation.

Figure 2. Adapted from Patterson Kirk Wallace

Figure 3. Adapted from Hear by Right/Roger Hart/Arnstein

<table>
<thead>
<tr>
<th>Level</th>
<th>Description</th>
<th>Example</th>
<th>Evaluation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consultation</td>
<td>Asking views and using these views to inform decision making.</td>
<td>Questionnaires, surveys, focus groups, feedback from service users.</td>
<td>Simple and safe but no commitment to act on findings.</td>
</tr>
<tr>
<td>Collaboration</td>
<td>Active ongoing partnership with service users.</td>
<td>Service users devising methodology, collecting data implementing change.</td>
<td>Can be time consuming and expensive. May also require staff to learn additional skills.</td>
</tr>
<tr>
<td>Service user led</td>
<td>Focus of power and decision making is with service users.</td>
<td>Service users lead the project including the topic and methodology.</td>
<td>Can be innovative and provide new information which might not have otherwise been uncovered.</td>
</tr>
</tbody>
</table>


Figure 4.
Appendix 4:
Patient and public involvement guides, NCI’s organisational standards

Organisational Competencies

1. People: Roles and responsibilities for PPI are clearly defined, visible and effective throughout the organisation, including leadership at all levels.

Indicators

1.1 There are named executive and non-executive directors at board level with explicit responsibility for PPI across both commissioning and provider organisations.

1.2 The organisation has named individuals responsible for defined PPI activities across the organisation. This includes a named individual responsible for coordinating PPI activities and a named individual with the duty to lead and strategically manage a PPI system.

1.3 PCTs, as commissioners, should ensure that there are named individuals with responsibility for PPI in all stages of the commissioning cycle.

1.4 At directorate/unit/team level there are named individuals with responsibility for PPI.

1.5 All staff and volunteers within the organisation know their individual responsibility for PPI.

1.6 Patients and carers with formal PPI links to the organisation have clearly defined role descriptions covering the scope of their involvement with the organisation.

2. PPI strategy and vision: There is an explicit strategic framework that makes clear the organisation’s commitment to PPI.

Indicators

2.1 There is a publicly available and board approved document that sets out the organisation’s vision for PPI.

2.2 The organisation (whether a commissioning or provider organisation) has a defined set of objectives for PPI activity.

2.3 There is a dissemination strategy and implementation framework for PPI activities, outcomes and impacts.

2.4 There is a statement of PPI principles for the organisation.

2.5 As the commissioner, PCTs should ensure that commitment to PPI is explicit in service level agreements and contracts.

3. PPI structures: Structures are in place at all levels of the organisation that facilitate dialogue and communication with patients, carers, the wider community and the public.

Indicators

3.1 The formal committee structure of the organisation allows flows of information to and from patients, carers, the wider community and the public and the organisation’s board.

3.2 There are policies in place to support PPI activity including:
   - a reimbursement policy
   - a reward and recognition policy for involved users
   - a policy about developing information for the public
   - a policy or policies outlining governance arrangements for PPI
   - a policy or policies that outline health and safety arrangements for PPI
   - a policy on support available to involved users
   - a commissioning public information strategy.

3.3 There is a training programme in place to support PPI including:
   - inclusion of PPI in induction
   - training of patients and public volunteers
   - training for the existing workforce (including commissioners) in elements of PPI
   - media handling.

5 NHS Centre of Involvement 2009
4. PPI processes: Process are in place at all levels of the organisation that enable patients, carers, the wider community and the public to effectively influence the planning, delivery, development, review and decision-making about changing and improving healthcare services.

Indicators
4.1 The organisation has clear protocols in place to demonstrate how patients, carers, the wider community and the public (including hard-to-reach groups) are involved in the end-to-end commissioning process.

4.2 The organisation is able to demonstrate that it uses a range of appropriate methods to gain feedback about the entire range of services it commissions or provides from appropriate people.

4.3 The organisation is able to demonstrate that it evaluates both the experience of involvement, the outcomes of activities and their impact on the organisation, staff, patients and the public.

5. Partnership working: The organisation has clearly defined structures and processes in place that enable effective dialogue with partner organisations at local and regional levels.

Indicators
5.1 The organisation has defined pathways mapping how it works with the Local Authority to undertake:
   - the Joint Strategic Needs Assessment
   - the Comprehensive Area Agreement
   - the Local Area Agreement.

5.2 The organisation has defined pathways mapping how it works with:
   - the Local involvement Network (LInk)
   - other voluntary and community organisations
   - disease specific interest groups
   - hard-to-reach groups
   - overview and scrutiny.

5.3 The organisation has defined pathways mapping how it works with other health and social care partners working within the local health and social care economy including:
   - the Strategic Health Authority
   - other health care organisations
   - social care providers
   - independent contractors and independent providers.

5.4 PCTs demonstrate through local community profiles that they proactively identify and seek out communities that experience the worst health outcomes, and through dialogue and engagement raise local health aspirations.

6. PPI monitoring and evaluation of effectiveness: Systems are in place that monitor PPI activity and evaluate effectiveness and impact and which influence future PPI planning.

Indicators
6.1 The organisation accurately maps and records all PPI activity on a continuous basis.

6.2 The organisation is able to quantify PPI activity and demonstrate the diversity of individuals and groups it has involved in which activities.

6.3 The organisation has clearly defined impact metrics defined for PPI and actively collects data around these metrics.

6.4 The organisation has systems that show how PPI metrics influence, develop and build the organisation and future PPI activity.

6.5 PCTs are able to demonstrate the impact on commissioning activity of patient and public survey data.
Appendix 5:
CAPP’s promotional poster

Are you interested in helping us to improve the quality of health services in Sheffield?

- Do you enjoy working with other people as part of a team?
- Do you have some time to spare?
- Would you like to learn more about clinical audit and how it is used to help us improve the quality of our services?

We are now looking for new volunteers to join the Clinical Audit Patient Panel.

To find out more please contact:-

**XXXXXXX Xxxxx**, Senior Clinical Audit and Effectiveness Facilitator
Tel: xxxx xxxxxx Email: xxxxxxxxxxxx

Or

**XXXXX Xxxxxxx**, Volunteer Manager
Tel: xxxx xxxxxx Email: xxxxxxxxxxxxx