Patient and Public Involvement

Toolkit for Staff

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SECTION 1

TOOLKIT FOR INVOLVING PATIENTS AND THE PUBLIC IN NHS LEICESTER CITY

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WHAT IS PATIENT AND PUBLIC INVOLVEMENT (PPI)?

PPI is the active participation of patients, users, carers, community representatives and the pubic in the development of health services and as partners in their own health care. PPI is broader and deeper than traditional consultation. It is giving local people a say in how services are planned, delivered and evaluated, by developing good communication with them, providing the information to make informed choices about their care and working in partnership to make decisions about service improvement.

For consistency, when we refer to 'patients and the public' we refer to patients, users, carers, relatives and the public as potential users of services.

NHS Leicester City (PCT) is committed to Patient and Public Involvement by ensuring that all decisions around service design and delivery will explicitly take into account the views of patients and the general public in Leicester. We recognise that this will improve the quality of our decision making and lead to services based around the needs of patients

WHY THE TOOLKIT?

The toolkit for Patient and Public Involvement (PPI) has been developed to provide guidance, to manages and staff in NHS Leicester City on how to effectively involve patients and the public in health care planning and delivery.

WHY INVOLVE?

NHS World Class Commissioning Competency 3

'To proactively seek and build continuous and meaningful engagement with the public and patients, to share services and improve health'

The Operating Framework 2008/09

'..Commissioners have a responsibility to ensure that their local communities have the opportunity to be fully engaged in the decisions that they take, and to take greater efforts to communicate what they are doing and why to their populations

SECTION 2

WHAT IS PATIENT AND PUBLIC INVOLVEMENT (PPI)?

Most people will need to use health services at some time in their lives and when they do so they need to be confident that the services they receive are focused entirely on their needs.

Benefits to patients and the public:

- Helps improve communication between patients and staff

- Patients, carers and their families have a better understanding of their conditions and treatment plans to achieve better outcomes

- Increases understanding of patients and the public about the health service.

Benefits to staff and NHS LEICESTER CITY

- Builds trust and better communication between patients and staff

-
- Provides information about patient experience to inform planning and service improvement

- Helps the PCT to provide accessible and responsive services based on local experience and need

- Enhances the development of patient confidence in the local NHS.

A legal requirement:

Section 242 of the National Health Service Act 2006 states:
"Each relevant English body must make arrangements, as respects health services for which it is responsible, which secure that users for those services are, whether directly or through representatives, involved (whether by being consulted or provided with information, or in other ways) in –
  - d. *The planning of the provision of those services.*
  - e. *The development and consideration of proposals for changes in the way those services are provided, and*
  - f. *Decisions to be made by that body affecting the operation of those services"*

What does is mean to the NHS?

Commissioning in the NHS is increasingly locally driven, which means PCTs need to have robust commissioning processes that are informed and influenced by the views and opinions of local people. **World Class Commissioning** (WCC) sets out the common attributes that will characterise PCTs.

Commissioners act on behalf of the public and patients. They are responsible for investing funds on behalf of their communities, building on trust and legitimacy through the process of engagement with their local population

WHY INVOLVE PATIENTS AND THE PUBLIC?

There are many reasons why it is important to involve and consult patients and the public.

First and foremost: it is the law. The Local Government and Public Involvement in Health Act 2007 places a legal duty on National Health Service organisations to involve and consult patients and the public in the planning of service provision, the development of proposals for change and decisions about how services operate.

However, this is not just about fulfilling a duty or ticking boxes. It is about understanding and valuing the benefits and positive outcomes, both financial and non-financial, of involving patients and the public in the planning and development of health services.

Section 242 of the National Service Act 2006 which supercedes Section 11 of the Health and Social Care Act and the wider Patient and Public Involvement system, of which it is part, will help to make sure that there is transparency and openness in procedures for involving and consulting patients and the public.

Beyond these there are other valid reasons for involvement and consultation:

✓ Services are designed and adapted to respond better to people's needs

✓ A consultation allows alternative proposals to be developed

✓ Major decisions are more transparent and the process for reaching them is understood

✓ Trust and credibility are built between communities and the health service

✓ Consultation will help plan services to meet patient and public expressed needs and expectations

✓ Patients and the public can set performance standards relevant to their needs and values

✓ The experience of patients', the public and local communities knowledge can be used to benefit others

✓ Better decisions are made because more people's views, perspectives and Suggestions are heard

✓ Patients and the public have a right to a say in decisions and policies on how health services are delivered locally

✓ Greater Patient and Public Involvement will lead to greater openness and accountability within the Primary Care Trust, which will enhance the legitimacy of decisions about local health services

✓ Patients sense of ownership and control of health services is improved when they are involved in planning and delivery decisions
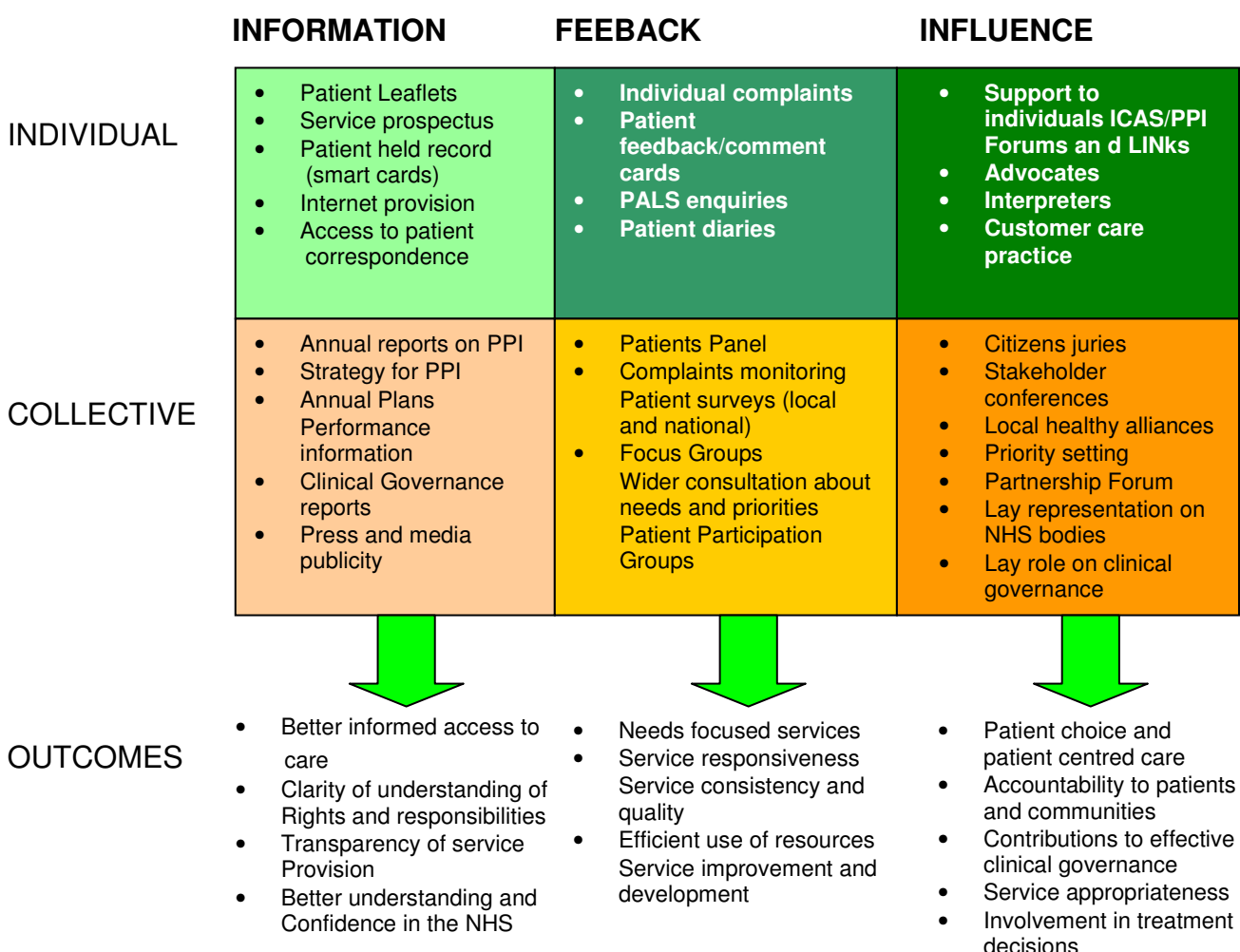
SECTION 4	TOOLKIT FOR INVOLVING PATIENTS AND THE PUBLIC IN NHS LEICESTER CITY

LEVELS OF PATIENT AND PUBLIC INVOLVEMENT (PPI)
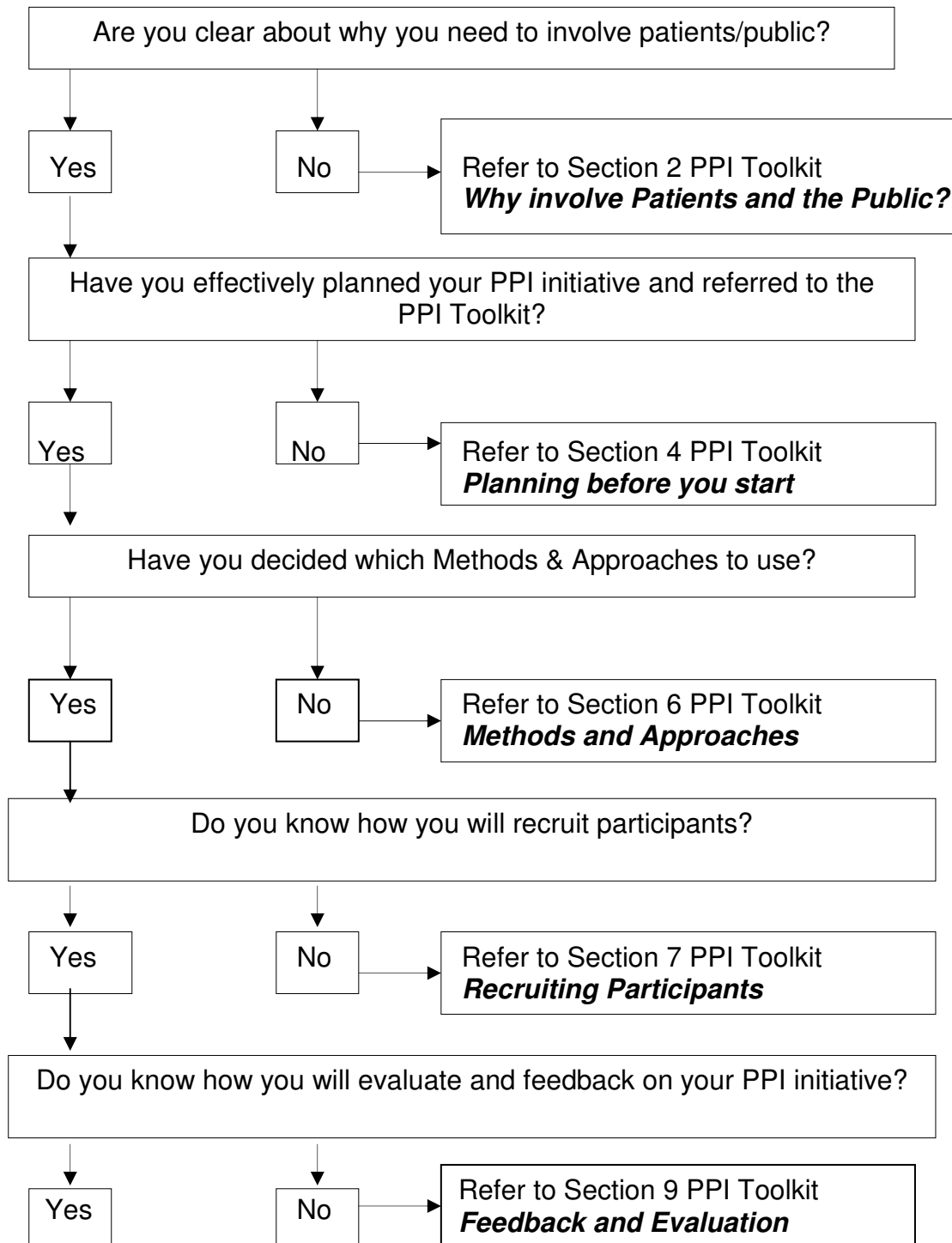
Levels of involvement

This toolkit is based on the Welsh Assembly Signposts document whereby involvement is covered across 3 levels – information, feedback and influence for both individual and collective involvement.

	INFORMATION	FEEBACK	INFLUENCE
INDIVIDUAL	• Patient Leaflets • Service prospectus • Patient held record (smart cards) • Internet provision • Access to patient correspondence	• **Individual complaints** • **Patient feedback/comment cards** • **PALS enquiries** • **Patient diaries**	• **Support to individuals ICAS/PPI Forums an d LINks** • **Advocates** • **Interpreters** • **Customer care practice**
COLLECTIVE	• Annual reports on PPI • Strategy for PPI • Annual Plans Performance information • Clinical Governance reports • Press and media publicity	• Patients Panel • Complaints monitoring Patient surveys (local and national) • Focus Groups Wider consultation about needs and priorities Patient Participation Groups	• Citizens juries • Stakeholder conferences • Local healthy alliances • Priority setting • Partnership Forum • Lay representation on NHS bodies • Lay role on clinical governance
OUTCOMES	• Better informed access to care • Clarity of understanding of Rights and responsibilities • Transparency of service Provision • Better understanding and Confidence in the NHS	• Needs focused services • Service responsiveness Service consistency and quality • Efficient use of resources Service improvement and development	• Patient choice and patient centred care • Accountability to patients and communities • Contributions to effective clinical governance • Service appropriateness • Involvement in treatment decisions

PLANNING BEFORE YOU START

In order for PPI to be successful, it is important that there is careful planning at the outset. The PPI and Communications Team are available to help you plan.

Are you clear about why you need to involve patients/public?

Yes	No →	Refer to Section 2 PPI Toolkit ***Why involve Patients and the Public?***

Have you effectively planned your PPI initiative and referred to the PPI Toolkit?

Yes	No →	Refer to Section 4 PPI Toolkit ***Planning before you start***

Have you decided which Methods & Approaches to use?

Yes	No →	Refer to Section 6 PPI Toolkit ***Methods and Approaches***

Do you know how you will recruit participants?

Yes	No →	Refer to Section 7 PPI Toolkit ***Recruiting Participants***

Do you know how you will evaluate and feedback on your PPI initiative?

Yes	No →	Refer to Section 9 PPI Toolkit ***Feedback and Evaluation***

Getting started

Establish a planning team

Bring together a small team of people who are important to the exercise (to include reps from PPI; Commissioning; Communications).
It is essential to have objectives and to be clear how the involvement is going to affect the service and influence decision making.

Consider the following questions when planning a PPI activity

- ✓ What information is required?
- ✓ How is the information going to be used?
- ✓ What resources are available?
- ✓ Who will you involve?
- ✓ What method will you use?
- ✓ How will you prepare your team?

Choose the right approach

Your method of consultation or involvement should match both your purpose and your target audience. This should flow directly from your planning.

Communicate your plans and prepare your team

Consider how your will communicate your plans to everyone involved and throughout the organisation

Evaluation

Consider and plan how you will evaluate the process and provide feedback to all involved

SECTION 6	TOOLKIT FOR INVOLVING PATIENTS AND THE PUBLIC IN NHS LEICESTER CITY

STAGES OF PATIENT AND PUBLIC INVOLVEMENT (PPI)

Ladder of Involvement

The ladder diagram below shows the different stages of involvement. It is helpful to view this as a continuum from just **information giving** to **full involvement**. It is essential during the planning stages that the appropriate levels of involvement are agreed these can then be implemented using the methods and approaches shown in this toolkit.

PARTNERSHIP - Membership of commissioning groups; Overview and Scrutiny Committees; Patient Participation groups

PARTICIPATION - Expert patients; Health Panels; shadowing patients; Story telling

FORUMS FOR DEBATE – Focus Groups; Interest Groups Workshops and Panels; Rapid Appraisal; Public meetings

GETTING INFORMATION – Patient Surveys; Interviews; Questionnaires; Open Surgeries

GIVING INFORMATION – Exhibitions; Leaflets and written documents; Web-based information; The Media

METHODS AND APPROACHES

Methods and Approaches

There are a variety of ways of finding out what patients and the public thinks and what they want. Some methods are simple and cost relatively little: others can take months and cost thousands of pounds.

Before choosing a particular method, a number of issues have to be considered:

> - **What information is required**
> - **How will the information be used**
> - **How much time is available**
> - **What resources are available**
> - **The nature of the service.**

It is important not to rely on a single method and assume that all that needs to be done is being done.

During the consultation on our PPI Strategy we asked patients and the public how they would like to receive information about local health services and also have they would like to give their views on local health services, this is what was said:

How would you like to receive information about local health services?	How would you like to give to views on local health services?
66% Newsletters	49% Questionnaires
34% Local Media e.g. Leicester Mercury	41% Post Surveys
24% Radio	23% Local Meetings
19% Leaflets	20% Interviews
17% Website	17% On line
4% Email	9% Focus Groups

PLEASE REFER TO THESE RESULTS WHEN PLANNING YOUR ACTIVITY!

METHODS AND APPROACHES

Giving Information - Exhibitions

Definition: information given in a visual form.

Pros	Cons
You may reach members of the public you may not normally reach.	You provide the public with the opportunity to give you their wide-ranging agenda. You may not be able to respond.
If staffed it provides the opportunity for representatives of the organisation to exchange information with the public.	If you choose the wrong site you will waste time and money.
A good opportunity to raise the profile of the organisation and publicise what it does.	Resource intensive if staffed all the time.
A comments book encourages people to respond there and then.	An unrelated response can set the tone for future contributions and doesn't allow an opportunity to discuss the reason for the response.
An opportunity to give the public other relevant information to take away or point them in the right direction.	

If you do decide to mount an exhibition you will need:

- Careful advanced planning
- Venue to be easily accessible, near places people will be visiting e.g. shops
- Best to be staffed at all times by the right people
- To be actively promoted e.g. press/radio ads, posters, flyers etc
- To look good, professionally designed
- To be interactive with the public
- Right amount of information to enable people to make informed comments or be directed to further information sources
- Information in different languages – use no jargon or abbreviations
- Include photos, maps, diagrams and models, use computers, TV monitors, Videos

METHODS AND APPROACHES

Giving Information - Exhibitions

ACTION	HOW	NOTES
Is the site relevant to the locality of the services being consulted upon? Is it where local people go?		
Has an individual been given responsibility for preparing and co-ordinating information for the event?		
Do you need a leaflet or other handouts?		
Do you need interpreters?		
How do you ensure the exhibition looks attractive and welcoming?		
Opening times?		
Are staff prepared to work these?		
Can the event be left unattended?		
How to record comments		
Are the staff well briefed?		
Do you need feedback to staff involved? How to do this?		
Are there providers whose expertise can be used e.g. health promotion?		
How will the messages from the public be dealt with and acted on?		
How to formally evaluate the event?		
Is the purpose of the event clear to everyone involved at the outset?		

SECTION 7	TOOLKIT FOR INVOLVING PATIENTS AND THE PUBLIC IN NHS LEICESTER CITY

METHODS AND APPROACHES

Giving Information – Leaflets and written documents

Style will depend on the target audience. The documents **must** be open and honest. When you are looking at producing any leaflets or written information for dissemination to publish you should refer to *Good Practice Guide to Communications: A guide for employees of NHS LEICESTER CITY* appendix 2 of this document.

Pros	Cons
A document may be seen as a starting point in a consultation.	A document becomes outdated quickly.
It outlines the organisation's position.	May be seen as a 'fait accompli'.
It is an accepted way of disseminating information.	There is no guarantee it will be read.
An opportunity for the organisation to make a statement.	The language may be inappropriate.
Public relations value.	Will a document really lead to action/change?
Keeps the public informed and aware Of the issues.	Sometimes there are too many around - overload!
It is a record of the organisation's position at that point in time.	Can be seen as expensive.

If you want to go ahead:

- Is this the best way to give information to people?
- The proposal outlined in the document should not be written in isolation and should be followed up with an action plan
- Ideally a document should be tested with a range of people from the target audience before it is published
- A consultation document should be followed by a strategic document outlining the changes that have been made as the result of the involvement and consultation and the next steps
- Information must be accurate, understandable and targeted
- What other information do people need to put in the document for context?
- Are you clear on who the audience is and how to reach them?
- Need to give the right amount of information. not too little, not too much
- The document is part of the process, not the process itself
- The production of a clear readable document is a specialised resource intensive task

METHODS AND APPROACHES

Leaflets and Written Documentation - Checklist

ACTION	HOW	NOTES
Consult **Good Practice Guide to Communications: A guide for employees of NHS LEICESTER CITY** available on PCT shared drive.		
It needs to look attractive		
Plain English, jargon free. Do you need editorial skills?		
Are you going to produce a summary?		
Do you need either the main document or summary translated?		
Do you need to consider other media e.g. audiotape, video, Braille etc?		
Obtain patient feedback on content to ensure information is understandable – use PPI database membership		
How is it to be distributed?		
Do you need posters to tell people about it?		
Will you use local media to advertise it?		
Would built-in response forms be a good way to get feedback		
If it is draft it should say so on each page		
Is the format and length suitable for the target audience?		
Do you need a glossary?		

METHODS AND APPROACHES

Giving Information – The Press and local media

If you are considering using the Press or local media this should be discussed with the Communications Manager in the first instance.

When we asked patients and the public how they would like to receive information about local health services the Press and local media were popular choices, this includes local publications produced by groups and organizations as well as local papers such as the Leicester Mercury. The Communications Team can advise you on what's available locally.

Pros	Cons
A fast and effective way of bringing issues to people's attention.	You can only get a simple message across.
You can reach a wide audience or target specialist publications.	Despite efforts you may not get into print.
You can build up a relationship with reporters for the future.	You cannot control outcome, you can only try to influence it.
	You can easily be misquoted if not putting in an ad.
	Can be very expensive.

If you do decide to use the Press:

- Will you pay for space or send a press release that you hope will be used.
  - Follow up press releases with a phone call
  - Would holding a press conference be more effective?

METHODS AND APPROACHES

Giving Information – The Press and local media

USING THE PRESS - CHECKLIST		
ACTION	**HOW**	**NOTES**
Consider a press launch or a press conference		
If you are not sure learn about press releases or setting up a press conference e.g. use Communications Manager		
Consider submitting photos to press. NB professional standard		
Make sure key people are willing to talk to the press for follow-up Interviews		
You need a protocol for dealing with any complaints that arise via the Press		

METHODS AND APPROACHES

Obtaining Information - Introduction

Ethical approval may be required when considering obtaining information directly from patients. In this respect it would be good practice to seek advice from the local ethics committee prior to commencing this type of exercise.

There are a number of Forums across Leicester that can be used when obtaining information. These can be used to build a picture of the community's priorities. They can be used to get a measure of public opinion on a specific issue.

Local Forums to be considered when obtaining information:

Within NHS LEICESTER CITY	Partner organisations

PPI Consultation Database
    273 individual members
     35 local organisation members
	Voluntary Action Leicester

	UHL Membership
Leicester Peoples Panel – 700+ members	UHL Patient and Public Involvement Forum
Leicester Patient and Public Involvement Forum	Leicester Partnership Public Involvement Forum
Local Involvement Network LINks (from April 2008)	Leicestershire County and Rutland Public Involvement Forums
Patient Participation Groups	Local Faith Groups/Special Interest Groups

HOW TO PATIENTS AND THE PUBLIC WANT TO GIVE THEIR VIEWS ABOUT LOCAL HEALTH SERVICES?

The results of the PPI consultation tell us people want to give their views via:

49%	Questionnaires
41%	Postal Surveys
23%	Local Meetings
20%	Interviews
17%	On line
9%	Focus Groups

METHODS AND APPROACHES

Obtaining Information – Questionnaires & Surveys

Surveys – a survey is a process to elicit the view of a population. A survey can combine two, or in some instances, three different research techniques such as focus groups, face to fact interviews and/or postal surveys.

Pros	Cons
A way of gathering relevant and quantifiable information.	Not good for qualitative information.
Information obtained will be relevant to the issue.	Not in-depth, no opportunity to explore ideas/issues/experiences further.
If well done information can be collected from large numbers or representative samples.	Could be a low response rate or unrepresentative sample.
Can be done face-to-face but increased costs.	Provides only a 'snapshot' in time.
Flexible and adaptable to a large number of issues.	Can be administratively unwieldy.
Can give base-line data on something to be monitored or measured against.	Cost: professional help may be needed to design and do the survey.
A professional organisation would give more independence to the results.	Would need to be available in a variety of formats and languages and would need to enable responses in appropriate format/language
Can be carried out with a specific group/community e.g. disease specific or race/gender specific	

If you want to go ahead:

Is the topic area appropriate i.e. not sensitive material?
Is information required quantifiable or able to be categorised?
Are the people you want to engage likely to fill in the questionnaire?
How large a sample?
Do you have a database or sampling frame of people you want to collect?
information from?
Do you want free text boxes to allow respondents to add comments?

METHODS AND APPROACHES

Obtaining Information – Questionnaires & Surveys

OBTAINING INFORMATION –SELF COMPLETED QUESTIONNAIRES CHECKLIST

ACTION	HOW	NOTES
What do you want to find out?		
Who is the target audience?		
Do you need help with sample size/ representation?		
How to distribute the questionnaire. e-mail, web site, postal?		
Have you time to collect answers in person or will you use postal services?		
Who will decide on the questions?		
Who will do the data analysis?		
Will you need outside help for this?		
Will the information be of any use if low response rate?		
Could you find methods to improve response rates, e.g. incentives?		
Will you send reminders?		
How to feed back outcomes to the respondents?		
Will you be offering interpreting services?		

METHODS AND APPROACHES

Obtaining Information – Questionnaires & Surveys

SEMI-STRUCTURED ONE-TO-ONE INTERVIEWS INCLUDING DISCOVERY INTERVIEWS can be completed on the telephone. Covers pre-set topics without pre-set answers. Qualitative data produced.

Pros	Cons
Obtains relevant information.	Interviewing skill required.
Target specific respondents: good population cross-section.	Need to sample enough people to generalise results.
The structure allows comparisons.	Expertise in preparing questions so they are not prescriptive.
Allows freedom to explore general views and perceptions in detail.	Data analysis skill needed for qualitative data.
Provides a framework for the interview.	Can be difficult to organise times and dates of interviews.
Can use staff from other areas of work/external organisation to do the work as it will add independence.	Cost, time consuming and resource intensive.
Can be a useful method for getting into sensitive topics.	

If you decide to go ahead

Be you clear about what you want to find out?

Do you want to collect comparative data as well as explore experiences and views in a less structured way? If so this is the right method.

How much time staff capacity and money do you have?

METHODS AND APPROACHES

Obtaining Information – Questionnaires & Surveys

OBTAINING INFORMATION – SEMI-STRUCTURED ONE TO ONE INTERVIEWS -   CHECKLIST

ACTION	HOW	NOTES
Who will prepare the framework for discussion?		
What are the key points to cover?		
Will interviews be face-to-face or by phone?		
Where will the interviews take place?		
Do you require interpretation and translation services to carry out the interviews?		
Who will do them?		
How do you recruit the interviewees?		
How many interviews do you want to do?		
How will you analyse the data?		
How will you present feedback?		
Who will prepare the framework for discussion?		

METHODS AND APPROACHES

Forums for Debate – Focus Groups

FOCUS GROUPS

A Focus Group is a discussion led by a facilitator with (up to 12) people invited to discuss specific issues or topics. Groups often focus around people of similar age, sex, race or experience. A note take should be present or discussions could be taped and transcribed.

Pros	Cons
Interaction may produce new ideas.	Group norms may inhibit some members: need good facilitation to overcome this.
Useful for providing an overview or for identifying issues for future discussion.	Does not generate 'evidence' as such.
Participants can be recruited to specific criteria.	Mix of participants may not work well depending on the topic.
Allows a framework for discussion, but content emerges from inter-action of group members.	Not a rigid process so difficult to make comparisons between groups.
Skilled facilitation can help all views to be heard.	Cost of employing facilitator and note taker.
Facilitator can interact directly with the group and provide clarification, information and interpret non-verbal responses.	Confidentiality a problem: need group rules to be formulated at the start.
Can empower participants.	Mixed groups of lay and professionals may need special handling.
Can include people with literacy/language problems.	May be difficult to find a facilitator with a range of language skills.
Can reach non-English speakers if the right facilitator found.	May need to hold a number of groups to validate findings between groups.
Can provide in-depth information on views and feelings.	Gender, age, ethnicity of facilitator may influence the discussion.
Can elicit views of those who think they have nothing to say.	Not all those invited may turn up. Optimum size 8-10.
Can be a learning experience for all.	
Can bring similar people together - group may be sustained.	

If you decide to go ahead

What sort of question do you want answering: 'why', 'how many', 'what'? E.g. why people hold a view, how many hold a certain view or what are the issues/solutions?

Focus groups help understand what views people hold and to explore why: they do not tell you how many share this view.

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METHODS AND APPROACHES

Forums for Debate – Focus Groups

FORUMS FOR DEBATE – FOCUS GROUPS CHECKLIST		
ACTION	**HOW**	**NOTES**
What criteria to use for selection of participants?		
How to recruit these, will you need professionals to do this?		
Is this method appropriate for the subject matter?		
Are you prepared to put time into developing the group e.g. training?		
Is the sample appropriate?		
Who will facilitate, are they trained?		
How much money can you spend?		
Independent facilitator from Primary Care Trust?		
Numbers in group, how many will you realistically attract?		
Who should be the note taker?		
What incentives?		
Paying travel costs, time, and care costs, catering?		
Venue?		
Best time of day?		
Would you video or audiotape the discussion? NB permissions		
What are the agreed ground rules e.g. respect confidentiality etc?		
What questions should you ask?		
What level of information do participants need?		
How long should each meeting last, maximum of 2 hours? NB special needs		
How to analyse the data?		
What will you do with the data?		
How will you feed back the outcomes?		

METHODS AND APPROACHES

Forums for Debate – Focus Groups

FOCUS GROUPS

Tips on Focus Groups:

7. Broadly homogenous groups in terms of age/sex/social class and other criteria. Who to include in a lay group and who to include in a professional group?

8. It may not be possible to achieve 1. A mixed group will prove more difficult to manage. Needs an experienced facilitator. If views widely vary consider using interviews instead.

9. Groups, which mix lay and professionals, need special ground rules re jargon and sharing expertise, better to call these groups' workshops or seminars.

10. These mixed groups may not work: lack of respect, inhibition by lay people can create tension or disillusionment.

11. Refusing to accept the validity of the patient's experience, inhibition of patients, arguments in defence will create disillusionment and an unwillingness to express opinions freely. This is not a suitable environment for the group to work in.

12. There may be benefits in opening up a range of varied views and values from experts and non-experts with consequent joint working to agree on compromises.

WHAT WE WERE TOLD DURING OUR PPI CONSULTATION

9% of respondents to our consultation said they would attend a Focus Group.

The Focus Group would need to be held in a local venue e.g. Community Centre or Health Centre

45% wanted the session held between 10.00am and 3.00pm

55% wanted the session held between 6.00pm and 9.00pm

METHODS AND APPROACHES

Forums for Debate – Self Help/Carer or User Groups

Self help groups, carer groups. Local voluntary organizations and service providers may have users willing to be consulted or wishing to be involved.

Pros	Cons
Reaches those with particular experience, concerns and expertise who may have particular reasons for wanting to be involved	Groups may be hard to identify, national organizations may not have local branches
Easier, quicker and cheaper to make contact	Well established groups may suffer from over consultation
Those with long term conditions will have special expertise in how to manage their condition and long-term experience of relevant services	Self help groups may not include a representative spread of the population in terms of age, gender or ethnicity
Advocates and carers can make a valuable contribution	User views may not always coincide with those carers or advocates. Both views are needed.

CARER GROUPS

These draw together people who have voluntarily taken on the role of caring for someone else who need extra help beyond what would normally be expected in a family. The cared-for person may be a child or adult with disabilities, learning disabilities or mental health problems, or a frail older person. Carers' groups maybe established by carers themselves, by staff at a carers centre or by professional service providers in hospital or community settings, including general practices.

Carer groups bring carers together

- For mutual support
- To enable them to have easier access to information that could help them
- To given them an opportunity to collectively raise issues of concern with service providers
- To given them a chance to discuss issues relating to caring
- To enable carers to have some time for themselves

Tips for successful carer groups

- Recognise that participants may have little time and energy. When and where the group meets and how it functions will need to take this into account
- Groups need support, enabling those present to determine the agenda
- Issues such as transport and care costs will need to be addressed to enable carers to participate
- Individuals who want to raise issues of concern may appreciate support to enable them to do so
- The atmosphere of carer group meetings needs to be accepting, supportive and undemanding

METHODS AND APPROACHES

Forums for Debate – Rapid Appraisal

RAPID APPRAISAL

This involved meeting and getting information from key local people who have particular knowledge of the areas and understanding of issues of local concern e.g. community leaders, manages of voluntary organizations, service providers, leaders of user groups.

Pros	Cons
Issues of concern and how they might be tackled are identified by local leaders	Lack on objectivity is a danger: talking with community leaders may not give you the range of views of their contacts.
Speed	Broad social as well as specific health issues may be raised that cannot be addressed by one single agency
Good response rate	Needs experienced researcher to collect and analyse data
Flexibility	A qualitative method – needs a trained researcher
Hears vies of those considered to be in the best position to understand local people	Personal bias may influence responses and how they are interpreted
A rapid way to achieve local ownership	Could raise false expectations
Data from various sources can be crosschecked and validated.	Danger of over-consultation: speaking to people who are repeatedly asked their views

TIPS FOR SUCCESSFUL RAPID APPRAISAL

- Collect information from written records, interviews and observations of the neighbourhood and observation of the neighbourhood or homes or workplace of those interviewed.
- Include any initial data available to you
- Advisable for the same person to collect and analyse data, provided she/he has appropriate qualitative research skills
- Validate date from one source by checking it with another
- Ask advice from local people to help you identify interviewees
- Clarify your objectives. What information is you seeking and why?
- Explain to those you contact how you will present your findings so that they can received feedback
- Evaluate the process and how its findings have influenced the service

METHODS AND APPROACHES

Forums for Debate – Public Meetings

PUBLIC MEETINGS

A public meeting is a meeting with an open invitation to the public. Discussion may be based on a set agenda or on issues raised at the meeting. For example, discussions on commissioning or an open discussion about the use of a health centre.

Pros	Cons
Opportunity to reach a wide range of people	Low turn out
High profile	No control over who comes so there may be problems in getting users that represent local population
Provides opportunity for joint work with Trusts, Local Councils etc.	Can be perceived as tokenistic
Enhances accountability as public can directly challenge those responsible for decisions.	
Problem areas highlighted	

TIPS FOR SUCCESSFUL PUBLIC MEETINGS

- Choose a suitable venue, easily accessible by public transport, well known to those you want to attract, with clear disabled access
- Hold the meeting on a day and time that suits those who would wish to reach (it may be best in the evenings or at weekends)
- Carefully design and target publicity to reach those who you wish to attract and allow sufficient time. User verbal networks and voluntary groups as well as posters and leaflets.
- Select a chair for the meeting who has the right skills and is perceived as clear and fair
- Ensure the professionals attending, including the chair, we well briefed and willing to answer questions raised.
- Arrange seating to encourage participation. If possible avoid hierarchical layout: use a circle or horseshoe arrangement
- Encourage speakers to identify and introduce themselves. Do not assume everyone knows a particular professional
- Ensure sufficient time is allowed at the meeting for local people to speak
- Ensure that those present have all the information they need to contribute effectively. Get the right balance between listening and informing.
- Consider offering crèche facilitites, suitable refreshments, travel expenses and care costs as needed.
- User a 'Personal Assistance' (hearing aid system) system to ensure that speakers are heard
- Evaluation the effect of each public meeting and what influence it has had on the service

METHODS AND APPROACHES

Forums for Debate – Public Meetings

WHAT PATIENTS AND THE PUBLIC HAVE TOLD US ABOUT PUBLIC MEETINGS

Hold them either between 10.00am and 3.00pm or 6.00pm and 9.00pm

Hold them in a public venue e.g. Community Centre with good access and parking facilities

Do not use jargon when talking to us!

METHODS AND APPROACHES

Participation - Citizens' Juries

12 -16 members of the public selected as a cross-section of the local community. They meet for several days to hear evidence. An independent moderator used.

Pros	Cons
People reflect broadly the characteristics of the local community.	Although drawn from local population this does not mean their views are representative.
Not necessarily stakeholders.	Some jurors may find it difficult to articulate views.
Detailed information given.	Can be difficult to be exact and focus on the question.
Value judgments may be involved in complex issues.	There may be a range of issues that need discussion: it may be difficult to decide which to open up to this method.
Jurors can call in others to get full information before decisions.	Huge amount of planning needed.
A measured process.	It is very expensive, not including staff time.
If the organisation makes a decision contrary to that of the jury this has to be justified.	The organisation is not obliged to act.
Aids openness in decision-making.	More difficult to reach a consensus and this may not be achieved.

PARTICIPATION – CITIZEN'S JURY'S CHECKLIST		
ACTION	**HOW**	**NOTES**
Is the Primary Care Trust board fully committed to this approach?		
Do you have the time to plan this?		
Who supports this exercise?		
Is it possible to supply the jurors with the kind of information they need?		
Are the witnesses willing to take part as planned?		
Is it an issue that can be influenced by this process or are there other limiting factors?		
Can you fund this?		
How will you recruit jurors?		
Where will it be held?		
Will you be able to access experienced support to run this exercise?		

METHODS AND APPROACHES

Participation – Expert Patients

Expert Patients

A group of people with a long-term medical condition who are prepared to share their experience and take part in self-management programmes. (link into NHS LEICESTER CITY Expert Patients Programme)

Pros	Cons
Easy to access.	Danger that the 'professional patient' may lose touch with their original experience.
A skilled and knowledgeable resource.	Some hold views that are limited or biased.
Expert patients can work independently to empower others.	Could restrict access to broader and more diverse range of patients.

If you decide to go ahead:

Are you clear about the issues you want to engage this group in?
Have you considered the resources needed e.g. training, expenses, and support?
Are you prepared not to be the expert?

PARTICIPATION – CITIZEN'S JURY'S CHECKLIST		
ACTION	**HOW**	**NOTES**
Do you know how to identify expert patients and to access them?		
Are you clear about the issues you are involving them in?		
Have you agreed what support and resources they will require?		
How will you evaluate their participation?		
How will the information be used?		

METHODS AND APPROACHES

Participation – Health Panels

HEALTH PANELS

A health panel is short term and designed for a very specific purpose. This could be used in a neighbourhood or locality area. It involves a group or out outside agency who takes the responsibility for recruiting and running the panel. Different patients represent the panel members and members of the community, who may be asked to answer specific questions about the service, may be asked to comment on a policy or on service changes. Feedback is then analysed and the results reported, and the panel is then disbanded once the work is completed.

Pros	Cons
Health panels offer a range of views on particular issues that require input from the wider population	The panels are mixed (gender, age, ethnicity) and this may be an issue if the topics cover sensitive service issues if health care is being prioritised
Panels are useful for views on resource allocation and priorities between set treatments	Panel members must be replaced after a pre-agreed number of panel sessions
Panels are made up of people recruited for their characteristics in terms of age, sex, ethnicity and location of residence rather than their interest in health service issues	Panel members are often given incentives to attend and respond. This adds considerably to the cost.
People are motivated by the incentive they receive to attend and often their developing interest and enjoyment of attending	If too many issues are discussed there will be little time to allow much debate or discussion and panel members may end up just giving their views rather than the reasoning behind them.
People of panels gain information about a wide range of issues	Professionals, who can only anticipate the type of information from their perspective, draw up the information given to panel members. It may be unknowingly selective or inadequate.

TIPS FOR SUCCESSFUL HEALTH PANEL

- Use an experienced person/organisation to carry out the recruitment
- Use an experienced facilitator to run the panels if face-to-face
- The issues should be an combination of your agenda and ideas from the panel
- Build in time and resources for planning and co-ordinating panels
- Panels generate a huge amount of data – make sure there is someone to analyse it
- Clarify the content of the report from the health panel and how it is going to be used

METHODS AND APPROACHES

Participation – Shadowing Patients

Shadowing Patients

Gives staff an insight into the patient's experience.

Pros	Cons
Allows first hand experience of a service.	Can be time-consuming.
Allows a chance to see different cultures and climates at work.	Needs a lot of preparation e.g. confidentiality, health and safety etc.
Strongly supports understanding and rapport between staff and patients	Needs commitment to be flexible and non-judgmental.
Is suitable for all levels of staff.	Shadow. can affect patient's experience.

If you decide to go ahead:

- Are you sure the organisation and the individuals are prepared to invest the time needed i.e. public transport, waiting times etc?

- How will you gain an insight and how might you use the subject of the shadowing to improve services?

PARTICIPATION – SHADOWING PATIENTS CHECKLIST		
ACTION	**HOW**	**NOTES**
Plan in advance: inform all involved, avoid artificial treatment of subject		
How to gain the user/patient's informed consent?		
Allow time at the end for the participants to reflect on the experience		
Think of health and safety and confidentiality arrangements		
Organise a pre-meeting to set ground rules		
Be aware of the need to let all know of this work. NB security issues		
Ensure the shadower is prepared to spend as much time as necessary with the subject		
Ensure subject gets feedback and can offer suggestions		
Follow up sessions of focus groups?		

METHODS AND APPROACHES

Participation – Story Telling

Story Telling

A patient tells their story, confirms details and an action plan is then drawn up.

Pros	Cons
You follow patient's agenda and listen.	Sometimes the patient has little to say relating to health care.
The interview is done by a colleague unconnected with the department providing care, thus avoiding bias.	It is very time consuming to organise and undertake.
It is taped so it is possible to gain an insight into people's thought processes.	It requires assistance from other staff.
Often things the professional thinks are problems are not high up on the patient's agenda.	The things worrying patients will need work and resources to fix.
It is patient focused.	You set the criteria for choosing the subject.
A useful training tool and useful where considering local changes.	Without a mechanism in place for feeding data upwards some of the benefits will be lost.

If you decide to go ahead:

- Are you clear how you will use the information?
- Have you considered the expectations of all participants?

PARTICIPATION – STORY TELLING CHECKLIST		
ACTION	**HOW**	**NOTES**
What criteria to adopt for selecting patients?		
How will you decide this?		
Is your department committed to this approach and is it clear how it will respond to issues raised?		
Has the department decided on how it will deal with difficult personnel issues?		
What procedures exist for agreeing processes that will bring about change in the Primary Care Trust?		
How will you feed back to individual patients involved?		

METHODS AND APPROACHES

Partnership – Community Development

Community Development

The community identifies its own health needs and social care needs and finds ways to address them.

Community development is about building active and sustainable communities based on social justice and mutual respect.

It is about changing power structures to remove the barriers that prevent people from participating in the issues that affect their lives.

Community workers support individuals, groups and organisations in this process on the basis of certain values and commitments.

NHS Leicester City Community Health Development Coordinators

NHS Leicester City has a team of Community Health Development Coordinators who work with local communities of Leicester.

METHODS AND APPROACHES

Partnership – Patient Participation Groups

Patient Participation Groups

A Patient Participation Group is a selection of patients and practice staff who meet at regular intervals to provide practical support for the practice and to contribute to the continuous improvement of services and facilities offered by the practice to patients.

What a Patient Participation Group is (and isn't)	
Patient Participation is:	**Patient Participation is not:**
Patients working with a practice to: ▪ Help themselves and other patients to take more responsibility for their health ▪ Provide practical support for the practice ▪ Contribute to the continuous improvement of services **Varied to suit local needs:** ▪ The activities of each group are determined by the needs of the community and in consultation with practice staff. **Based on co-operation:** ▪ It works by building a relationship between the practice staff and patients that break down barriers to communication ▪ It enables the sharing of information ▪ It can provide a springboard for public involvement in wider aspects of the NHS	**A Forum for complaints:** ▪ By providing a channel for communication, a PPG can reduce the risk of complaints. Many groups agree to forward concerns to the practice in confidence. In practice this is rarely needed. **Implementation of a pre-determined agenda (the government's or anyone else's)** ▪ The independence of Patient Participation groups is one of their major strengths. They informally accountable to all the patients in the practice and should therefore take a balanced view of needs. **A time consuming activity for practice staff:** ▪ Most groups are self-organising. Many undertake activities that help the practice staff **Only effective in rural practices:** ▪ In 1999 a survey showed more than 50% of groups were in towns and cities.

If you decide to go ahead
You can find out more information about establishing Patient Participation Groups by speaking to the PALS and PPI Manager. During our PPI consultation over 159 respondents (59%) said that they would be interested in joining a Patient Group. These names have been stored on a database and can be used with relevant practices when recruiting members

METHODS AND APPROACHES

Partnership – Large Group Processes

Large group processes
Appropriate for involving a wide range of stakeholders between 30 and 120. They are highly participative.

Pros	Cons
Emphasis on self-management in small groups.	Can be time-consuming.
Openness.	Processes take a lot of planning and organising.
Empowers participants.	Can be costly.
Everyone is equal and an expert.	
Individuals are experts in own lives.	
There are only facilitators: no other experts involved.	
Processes are consensual.	
Processes can bring together opposing groups.	

EXAMPLES OF LARGE GROUP PROCESSES

Future Search Conference
A community is able to create a shared vision for the future. It brings together those with power to make decisions with those affected by them to try to agree on a plan of action. The process involves up to 64 people forming 8 stakeholder groups. These are selected on the basis of knowledge, power to change services and those affected by outcomes of these decisions. A highly structured process over 2-3 days covering 5 stages: reviewing the past, exploring the present, creating ideal future scenarios, and identifying a shared vision. At the end an action plan is developed. This process requires at least one facilitator and a large room.

Open Space
A democratic process where an unlimited number of participants create their own programme of discussion around a central theme. It is effective in generating participation, learning and commitment.

Team Syntegrity
A process for enabling a large group to work in a democratic non-hierarchical manner to capture they're best thinking. Useful for groups, which are very diverse. Involves 30+ people over 3 to 5 days in facilitated thinking and dialogue

RECRUITING PARTICIPANTS

CHILDREN AND YOUNG PEOPLE

Children and young people have a right to be involved in issues that affect them, and can be consulted and involved effectively. Children and young people have valuable ideas to contribute to service development and healthcare delivery.

Possible ways to involve young people
- Community fun days   - Workshops in the community   - Health projects in schools   - Art and creative media projects   - Surveys   - Prize draw contests and drawing contests   - Leicester Youth Council

Community fun days, with free fun activities, can be successful ways to involve young people (and sometimes reach their parents) on a large scale. You can offer a variety of activities so that everyone is likely to find at least one activity that suits them. Make it clear in the publicity that the activities are free so that more will feel happy to come.

Workshops in the community, or a type of focus group, let you drawn on an already established group of children and work in an environment they know. Children are also more able to express themselves, and you can always ask then on the spot to clarify a comment that wasn't immediately clear or add useful detail. We have found this a very useful way of getting their views, and it can be a lot of fun for the group.

Health projects in schools are a good way to carry out either a short or long-term project. It must be said that arranging workshops in schools can be time consuming. Finding ways that your project or activity supports areas of the curriculum (PSHE or Citizenship especially) can help get a foot in the door at a school.

Art and creative media projects have elicited a good response from children and young people. They are attracted to information conveyed through posters, music, video and websites, and you can also work with them to do their own creative projects to express their opinions. They will learn skills, which can boost their self-confidence and employability in the future.

Surveys and questionnaires are generally less likely to interest young people, and in our experience convey only brief information. If you do design one, however, involve some your people in the process to make it more attractive. Children may prefer……….pictures and tick boxes to open-ended questions. Even drawing their idea work better for some children rather than reading or writing a long piece of writing – and this method may reduce barriers due to communication.

Prize draw contests and drawing contests can be a good incentive for your people to get involved and contribute their ideas. The contests can serve as a successful focus for recruiting more young people.

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SECTION 8

RECRUITING PARTICIPANTS

CHILDREN AND YOUNG PEOPLE

Important tips for success with all methods

1. Make sure that staff working with children have an enhanced criminal records bureau check, and that at least two workers are with children at any time. Make sure you comply with the relevant Child Protection Policies.

2. Go to where children and young people are. Tapping into established groups of children means less time spent on developing and recruiting groups, but also means you can build on already established relationships and work with children where they already feel comfortable. Going out to where children are also means having the support of the workers running the group.

3. Be honest and upfront with young people about any constraints that may limit what change they can affect (such as time, resources available, etc.); they will then learn to adjust to these constraints and propose more realistic ideas, and moreover, will help to build trust.

4. Think about what age group you wish to attract, and design the activity accordingly. In conveying information, user language appropriate for there age group and ability.

5. Be flexible! Things change in children's lives all the time, as does their attention span. It is always good in workshops to be prepared with several ideas abut what you would like to do, in case the young people aren't responding well or their circumstances change (or the age of the group is suddenly two people instead of the 15 you expected).

Having a flexible approach – positive yet realistic – helps children feel more comfortable. It also helps you to feel good about what you have achieved even if an activity was difficult or different to what you had expected.

7. Make it fun, with games, creative activities and a welcoming attitude. Going in ready to have a good time yourself can be helpful as you will then convey this to the young people. Games work well as icebreakers to help get a group warmed up and to let everyone get to know each other. Some games help to lift energy when it's low, others can help to calm and focus their attention.

7. Provide free refreshments and other goodies (balloons or stickers for younger children, music or vouchers for older ones), as this is a brig draw.

8. Venue: Choosing a venue where children and young people feel comfortable and able to enjoy themselves is important. Make sure it is somewhere they want to go to and that they can get to easily. Offering to pay for their travel expenses to venue helps.

10. Timing: If you are setting up an activity or event that it not linked in with the school curriculum (which is incidentally one possible approach), they need to take place after school, at weekends or during school holidays to attract greater numbers.

RECRUITING PARTICIPANTS

CHILDREN AND YOUNG PEOPLE

If you decide to go ahead

Consider speaking to some of the local organisations who currently work with children and young people including:

> Connexions
> Youth Voice
> Voluntary Action Leicester

Community Development Co-ordinators – there may be some local projects/groups that you can link into

WHAT LOCAL YOUNG PEOPLE HAVE TOLD US ALREADY

Rewording of documents for a young persons perspective

Hold small focus groups (mixed ethnicity and age) with young people to get their views or send them documents to view.

Large groups would not work as there is so much to say.

Use the internet or texting to inform young people

Visit schools to get views from children and young people

Use incentives whether it is free pizza at the end or a goody bag

In Leicester young people are trained as inspectors. Inspector training is where young people check plans for services, discuss future services in groups or sometimes visit services to assess them. This kind of engagement helps towards their assessments so the young people get something out of it.

School nurses can give information, especially during routine treatment i.e., jabs

OLDER PEOPLES GROUP

Older people make up the largest single group of patients using the NHS. People over 65 account for two-thirds of hospital patients and 40% of all emergency admissions. Too often they are treated in inappropriate acute hospital settings because there is nowhere else. Older people also worry about the prospect of deteriorating health, and can be anxious that they may not receive the care they need, sometimes because of their age. They are also distressed when service providers fail to respect their dignity and privacy – a problem which can occur at home or in a nursing home, as well as on the hospital ward. There can be particular problems for those from black and minority ethnic communities in accessing the services, which meet their needs and wishes.

There is a growing body of research evidence to indicate that social isolation and particularly loneliness are detrimental to health and can result in problems of depression and anxiety, as well poor health behaviours Many older people lose confidence in their ability to maintain social contact or valued activities, particularly if illness, the onset of disability, the effects of bereavement or other circumstances affect them. Often the barriers to independence are quite simple, but are not addressed because services tend to use standardised approaches focusing exclusively on physical and practical problems, which may overlook the individual circumstances of people's needs and attempt to slot them into prepared packages. Any support group needs to recognise this and provide a platform for them to talk about those other services.

Tips for successful involvement

- Work with existing older peoples' groups/voluntary organisations; i.e. Age Concern. Do no wait for people to come to you; go out, introduce yourself and let people recognise you.
- Being involved in the planning and/or delivery of health services is not always the most important issue. Try to link in with issues of interest to older people; i.e. personal care, pension, bereavement, so that people feel more stimulated to get involved.
- Always give feedback
- Always offer refreshments and travel expenses; the venue should be accessible

RECRUITING PARTICIPANTS

REFUGEES AND ASYLUM SEEKERS

Refugees and Asylum Seekers cannot be grouped into one single group:

In 1951 the United Nations Geneva Convention defined 'refugee' as a person who has left his/her own country and is unwilling or unable to return there "owing to a well founded fear of persecution for reasons of race, religion, nationality, membership of a particular social group or political opinion".

An asylum seeker is a person who has applied for asylum status in a host country. A refugee is a person who claim for asylum has been accepted and he/she is allowed to stay in the host country for indefinite time or for a definite period of time.

Refugees and asylum seekers differ accordingly to their immigration status, their nationality, their cultural background, language, social class, gender, age, sexuality and so on.

The consultation and involvement of refugees and asylum seekers in planning and/or delivering health care services have to take into consideration all these factors. Isolated and vulnerable members of the communities need sensitive and tailored approaches.

What information of refugees and asylum seekers can mean:

Mutual support

Improved understanding of how the health care system works and how to access the different services.

Give them a voice on how the services are organised and delivered.

Development of more accessible and appropriate services

Tips for successful refugees and asylum seekers involvement

7. Work with existing Refugee Community Organisations (RCO's) and target those individuals who are not connected with RCO's. Do not wait for people to come to you: go out, introduce yourself and let people recognise you.
8. Refugees and asylum seekers are more likely to have had negative experiences with the statutory agencies. Try to be informal and to reassure participants that their involvement will be confidential. Build trust with communities and individuals.
9. Language is one of the main problems. The use of interpreters and jargon-free language will help people to participate.
10. Provide information in the relevant languages or dialects.
11. Have a non-judgemental attitude towards people who have a different cultural and social background and behaviour. Respect their views and be, foremost, a listener to their problems, demands and needs. Be realistic and do not set peoples expectations too high.
12. Being involved in the planning and/or delivery of health services is not always the most important issue for refugees and asylum seekers. Often they face problems around immigration status, housing, isolation and insecurity: health is just one aspect of their problem. Try to link in with issues so that people feel more stimulated to get involved.

RECRUITING PARITICIPANTS

REFUGEES AND ASYLUM SEEKERS

Tips for successful refugees and asylum seekers involvement cont.

10. Always give feedback on people's contribution and on how their suggestions and ideas will be taken into account.

11. When you gather people together offer refreshments and travel expenses; the venue should be accessible and if possible provide a crèche for children.

12. Speak to those who work within the Assist Practice as this practice provides health services for both Asylum seekers and refugees and may be able to facilitate access to service users.

BME Communities and other people whose first language is not English

Evidence clearly shows that people from BME Communities tend to have poor take up of health services so it is important to consider potential services users and carers

- Avoid holding events on days that are celebrated by particular groups in the community
- Select appropriate community venues where people feel comfortable and times (checked with the community) when they can attend meetings or can be contacted
- Provide refreshments that are appropriate to people's religious and cultural needs Avoid making stereotypical assumptions about individuals or groups (ask them to identify processes to overcome barriers to involvement and for solutions)
- Provide information in 'plain English' (jargon and acronym free) that is appropriate to people's culture and language. Remember that some people may not read or write their first language. In addition to translated material, consider the use of audio/video tapes as a word of mouth
- To assist people to gain a better understanding of the issues under consideration think about sending out briefing information, in appropriate languages, in advance of any meeting
- Offer trained interpreters – contacts available via Ujala Resource Centre. Do not rely on a family member to interpret as this can place an unnecessary burden on them and will be inappropriate when dealing with sensitive or personal issues
- Tackle issues that particularly affect people from minority ethnic Communities
- Respect each other's differences
- Challenge discriminate such as racist language and behaviour, from whatever source
- Establish links with the relevant community group leaders

RECRUITING PARITICIPANTS

People with disabilities

- Consider the barriers to disabled people, remember that access is not only about physical access but includes attitude, use of appropriate language, information and confidence

- Ensure that any information provided informs people of full access details and invites them to notify their requirements e.g. personal assistant, special parking space. All information should be in accessible formats

- Ask disabled people for advice. Do not make assumptions about people's abilities or needs and remember that some impairments are hidden. e.g. mental health problems

- Avoid 'standing over' people in wheelchairs.

People with hearing impairment

- Offer British Sign Language (BSL) interpreters where appropriate (this can be arranged via Ujala Resource Centre)

- Provide a loop system at the venue (this allows people with suitably equipped hearing aids to have the background noise eliminated)

- Have a minicom available to enable telephone contact

- Consider the use of faxes, the internet / e-mail or a text phone number

- Remember that lip reading is a vital part of vocal examination.

People with mobility needs

- Provide disabled access and allow space for people who use wheelchairs when planning seating. Consider the layout of the building - stairs etc

- Make sure the transport provided is accessible

- Consider involving people in their own home or community group setting

RECRUITING PARTICIPANTS

People with sight impairment

- Have information available on audio tapes

- Make sure that signposts and information are put in large print and that all written signs are in dark lettering on a pale background. Black letters on a yellow background is often the preferred colour scheme

- Involve people in their home or community group setting

- Offer Braille transcriptions for Braille users

- Ensure venue is suitable for Guide Dogs.

People who use mental health services

- Involve people who use mental health services, not just their advocates

- Involve support workers and carers

- Understand the implications of the Mental Health Act.

People with learning difficulties

- Involve the relevant support groups and independent agencies

- Ask if the person has a health facilitator, family member or carer who they would like to be present

- Talk to, and look at, the person not the advocate or supporter who may be present

- Speak more slowly and be prepared to be interrupted and go over things again

- Have information available in an accessible format (e.g. straight forward, jargon free language, short sentences, large print, pictures)

- Link with Learning Disability Services in the community such as MENCAP

- Work with advocacy and self-advocacy groups

- Ensure people with learning disabilities are involved, not just advocates

- Check out the Department of Health's. Valuing People. Consultation and implementation work for effective ways of working.

RECRUITING PARITICPANTS

People in Custody – Prison Population

- Consult through Prisoner Forums or Councils

- Involve local Independent Monitoring Board

Gay, lesbian, bisexual and transgender communities

- Consider targeting through the gay press and leaflets rather than relying on local meetings

- Use local gay venues

- Internet

- Contact local gay organizations (PRISM Forum part of Leicester Lesbian, Gay, Bisexual and Transgender Centre)

- Use local gay and lesbian switchboards and contact lists

- Involve lesbian and gay health workers organisations, networks and Conferences

Homeless people and travelers

- Work with the relevant voluntary agencies, council departments and utilise health visitors.

- Link into the Homeless Primary Care Health Service based at the Dawn Centre

- Link into travellers service

DEALING WITH PATIENT FEEDBACK

Dealing with Patient Feedback

Feedback from patients and the public can be made in different forms, verbally, in writing, positive and negative. All feedback whether it be positive such as compliments or negative such as complaints needs to be notified.

NHS Leicester City currently receives patient feedback through many   different sources, two of the main ones being:

- Via the PALS Service
- Via complaints

Leicester City Patient Advice and Liaison Service (PALS) advise and support patients, their families and carers by:

- provide information on NHS services
- listening to concerns, suggestions or queries
- helping to sort out problems quickly

Handling Complaints

See NHS Leicester City Complaints Procedure.

If a complaint is made during a public involvement event:

- Listen, acknowledge but don't get involved in details. Do not try to justify actions of organisation but acknowledge patients feelings sensitively

- Advise on the PALS Service and signpost in the first instance

EVALUATION AND FEEDBACK

Feedback

This must be an on-going process throughout the participation project: it is of little value if only staff get this information. Sufficient resources need to be identified at the planning stage for the feedback process. How will the results of the exercise be disseminated?

This process can be seen in two parts:

The way in which the results are presented	Who the results will be presented to
• A report must be prepared based on the raw data not an interpretation of it • Summaries and fact sheets can be produced from the main report ▪ Remember your audience when presenting your results: different audiences require emphasis on different points.	• It is essential to give feedback to **everyone** who was involved in the consultation process **throughout the process** and advises them of subsequent actions taken in order to demonstrate genuine commitment by the PCT to patient and public participation. • Patients and Public involved in the consultation • Managers and staff within the Primary Care Trust • Directors of Trusts, Chief Executives and boards

Evaluation

There is currently no defined best method of evaluating participation exercises.

One suggestion is to define and measure outcomes. Defining outcomes gives credibility to and decisions made that are based upon them. The way in which outcomes are measured depends very much on the aim and the method of the project.

The following questions may help you evaluate a participation project:

- Were the participant's representative?
- Was the method used successful?
- Was the aim of the exercise achieved?
- Was the information collected used to inform service changes and/or planning?
- What lessons can be learnt for future patient and public participation exercises?

SECTION 10	TOOLKIT FOR INVOLVING PATIENTS AND THE PUBLIC IN NHS LEICESTER CITY

EVALUATION AND FEEDBACK

Feedback

Patient, user and carer feedback can be obtained from the following services provided directly by NHS Leicester City. The feedback is used to inform service change and improvement.

Patient Advice and Liaison Service (PALS) PALS are complementary to existing services and provide information and on the spot help for patients, their families and carers. PALS can be used to help resolve service users' concerns quickly and efficiently. PALS can also act as a catalyst for change and service improvement. If a patient or carer is not satisfied with the service they have received, but does feel they want to make a complaint, PALS is the ideal location for the query.	Where there is a more complex issues that requires follow-up or liaison with more than one agency then it is passed to the **PALS Team on 0116 295 7011.** **Complaints** Complaints received about services provided and commissioned by NHS Leicester City are acted upon through relevant referrals or that local resolution process. Complaints received are monitored and used to inform improvements and service planning.

Reporting back on involvement exercises to the Primary Care Trust

Section 242 of the Health Care Act 2006 places a duty on PCT's to progress Patient and Public Involvement in a systematic and coherent way.

Any Patient and Public Involvement exercise is an excellent way of improving the quality of services. It is important that the PCT has an overall view of what is happening with reference to Patient and Public Involvement within the PCT. The Trust Board considers PPI as a priority. Regular reports are sent to the Board to update them on progress. The PCT therefore needs to be aware of **all** patient and public activity that is going on across the organization so that it can be fed into the Trust Board reports. The Commissioning Framework indicates that all service planning/redesign and commissioning processes should include a PPI strategy and PPI involvement. The PPI and Communications Template can be used to effectively plan and record PPI activities within projects.

Any outcomes of involvement exercises need to be brought to the attention of the Primary Care Trust via the Patient and Public Involvement Manager and completion of the PPI and Communications Template. The template is included at Appendix 1.

The form should be completed at the end of all Primary Care Trust participation events and forwarded to, Patient and Public Involvement Manager. This information will be then be collated and reported both internally and externally.

REFERENCES
Section 242 Health Care Act 2006
Website: www.dh.gov.uk

Patient and Public Involvement Strategy Leicester City Primary Care Trust

Results from the PPI Consultation
NHS Leicester City

Signpost One: A Practical Guide To Public and Patient Involvement In Wales, 2001

Toolkit for Involving Patients and The Public Lambeth PCT

Involving Patients and the Public… A Toolkit for Staff Barnsley Primary Care Trust 2003

Public Involvement Toolkit
Wakefield West Primary Care Trust 2002

National Association for Patient Participation (NAPP)
Website: www.napp.org.uk
N.A.P.P. supports the aims of the Alma Ata Declaration that includes this Statement:

"The people have a right and duty to Participate individually and collectively In the planning and implementation Of their health care."