CHAPTER 1

Introduction

The toolkit series

The ‘toolkit’ series encompasses a number of books and a website published by Blackwell. The concept behind the books is to make complex health care topics accessible and easy to understand to those who need them, particularly:

- health care students
- clinicians
- users of health care research
- researchers
- commissioners of health services and research.

This book is the fourth in the current series of toolkits, which also includes the *Evidence-Based Medicine Toolkit*, the *Statistics Toolkit* and the *Searching Toolkit*. The writing team for this book is Julia Cartwright and Sally Crowe, both experts in patient and public involvement (PPI). The editing team is Douglas Badenoch, Carl Heneghan and Rafael Perrera.

Aim of this toolkit

The purpose of this toolkit is to help you undertake effective patient and public involvement (PPI) in your work. This could be clinical research, service redesign, policy development or commissioning activities.

This book will take you through the journey of involving patients, carers and the public, with chapters that address specific and important stages of the journey. At the end of each chapter there will be a key points summary table. A list of icons used throughout the book is given on page 14.

We have created resource lists at the end of each section that will help you locate useful resources. While all of the resources were checked before publication, PPI is an evolving and fast-moving world, with new groups, resources and ideas becoming available all of the time. Since going into production, the UK government has issued its White Paper on health

Patient and Public Involvement Toolkit, 1st edition. By © J. Cartwright, S. Crowe, R. Perera, C. Heneghan & D. Badenoch. Published 2011 by Blackwell Publishing Ltd.

(Department of Health, 2010), *Equity and Excellence*. 'No decision about me without me' is the strap line for this policy document which aims to put patients at the heart of decision making in the NHS. This toolkit is therefore a timely resource for those individuals who need to make PPI happen. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_117353.

Why have a PPI toolkit?

PPI is becoming much more integrated into service development at every level of health care, and increasingly is a common part of clinical health research. Despite these advances, PPI is often haphazard and inconsistent, with a plethora of individual but unconnected activities.

Therefore, we decided there is a need for a clear, simple toolkit that will help you to:

- **Identify** the purpose and useful outcomes of PPI.
- **Understand** how to run effective PPI programmes and how to engage constructively with patients.
- **Clarify** to those involved in a PPI programme what to expect from their involvement and how to make their voices heard.

EFFECTIVE PPI CHECKLIST

Some of the most effective PPI happens when:

1 There is a clear understanding of what is needed to enable effective involvement.
2 There is recognition of the likely barriers to effective engagement.
3 The purpose and benefits of involvement are clear to everyone.
4 There is attention to detail.

The language of PPI

One of the problems in PPI is the complexity of the language that is used. This has been recognized at the highest level:

> *The conflation of these distinct terms and the confusion about the purpose of involvement has led to muddled initiatives and uncertainty about what should be done to achieve effective PPI.*
>
> UK Parliament, House of Commons Health Committee Report 2007

Getting started

What is PPI?

Healthcare professionals working together with patients and the public to improve the health communities they serve.

health professional A health professional is an organization, team or person who delivers health care in a professional manner to any individual in need of health care services.

Why do PPI?

- To improve **access** to health services.
- To have a better **informed** public.
- To improve the **quality** of health care.
- To make better use of health care **resources**.
- To improve how health services are **measured** and **evaluated**.

Who can benefit from PPI?

- **Patients** if they see their views being considered and used to improve the quality of care for other patients.
- **Health researchers** if they see that the quality of their research design and outputs are improved by working with patients from the outset.
- **Health service managers** if the standards of service they design are patient friendly and reduce the level of inappropriate admissions to hospital.
- **Health professionals** if they see a reduction in attendance at specialist clinics because patients can better self-care at home.
- **Public** if they see that decisions about health care and services are transparent and accountable.

For this toolkit we use the following terms throughout:

Term	Definition
INVOLVE	To Inform. To consult. *'Surely we are at the heart of care and treatment? My experiences can help services improve'*
ENGAGE	To partner. To work directly with. *'I want staff to think about opportunities for PPI at the start of all projects'*
EMPOWER	To place authority for final decision making in the hands of the patient or the public. *'We would like to see more patients and public at senior management meetings and having a real input to future strategy'*

Sections will be colour coded throughout to help you see what level of PPI is being described or suggested.

The following words are prohibited from this toolkit:

- **Participatory** – we will write about working with people.
- **Stakeholder** – we will write about patients or public.
- **Client** – we will talk about patients or public.
- **Dialogue** – we will write about talking to patients or public.
- **Facilitate** – we will write about working together and sharing.
- **Partnership** – we will write about doing things together.
- **Lay** – we will write about patients and the public.

For further words that should not be used when communicating with patients and the public go to:
www.idea.gov.uk/idk/core/page.do?pageId=17636724

KEY TERMS

patient People who are under the care of clinical services, or have recently used these services.

carers People who care for others in an 'unpaid' and non-professional capacity.

public People who are not under the care of clinical services but who may have a view on those services.

patient involvement Involving people who have used health services.

public involvement Involving people as citizens who may or may not have used services.

National Health Service (NHS) The NHS is the name used to refer to the publically funded healthcare systems in Great Britain.

Primary Care Trusts (PCT) PCTs are part of the NHS. They provide some primary and community services and commission secondary care services.

Levels of PPI

Involvement is often referred to at different levels, suggesting different types of activity and outcome. In this book we will use involvement (rose), engagement (pink) and empowerment (red).

The following examples will help you to understand the different levels of involvement using different case studies.

- Designing hospital signs.
- Redesigning an outpatient service.
- A collaborative research proposal in cancer.
- Developing a patient information resource.
- A local public awareness campaign for flu.
- Commissioning a primary care service for mild to moderate depression.
- Determining local health priorities.

They illustrate the different settings for PPI involvement and show you how the different levels of PPI can work in practice. Without recognizing the different impacts PPI can have on health care, it may be difficult for you to envisage how you might incorporate it into the development of new services, research proposals and in determining priorities for local health services.

Each example is described from both patient and public perspectives. These themes will be repeated throughout the toolkit; it might be worth referring to them when you are about to investigate your own patient and public involvement project.

Designing hospital signs

INVOLVEMENT	Members of the public	An information leaflet is displayed in public areas informing the community that the local hospital will have a new sign and signage
	Patients	The local hospital patient user's group is asked where they think the new hospital signs need to be located
ENGAGEMENT	Members of the public	The communications director arranges a presentation of new designs for hospital signs to public bodies such as county and district councils. Feedback from the event is used to inform the final version of the hospital signage
	Patients	The communications director arranges a presentation to patient groups showing them proposed designs for the new hospital signage Feedback from the presentation is used to inform the final versions of the location and design
EMPOWERMENT	Members of the public	The Health Overview & Scrutiny Committee has received complaints that the local hospital signage is difficult to read and understand. This makes access to the hospital difficult for patients They raise the issue at a hospital trust board meeting which has public access and agree that they will work with local community groups to prepare designs which are user friendly, welcoming and correctly located They will conduct a 'before and after' survey to test their methodology to ensure that they add to the evidence base of positive user involvement improving access to health services
	Patients	The local hospital user group representative informs the hospital governing board that 45% of patients surveyed said that they could not read the hospital signage The user group, who has a trained expert in health communication design as a member, would therefore work with a team of patients, public bodies and a design team to work up a proposal for new, user-friendly signage

Redesigning an outpatient service

INVOLVEMENT	Public	Posters and leaflets displayed in public areas (and on the relevant web pages) inform the outpatient service users that changes are coming The Local Involvement Network is contacted about plans and invited to participate Previous satisfaction surveys and monitoring information are reviewed for feedback on out patient service
	Patients	The local hospital patient user group is asked what sort of out patient service they would like This could be achieved within an existing meeting, a specific focus group or with a short survey (web and/or paper based)
ENGAGEMENT	Public	A specific event is held showcasing ideas for service development, with an open invitation and targeting those who have already contributed Feedback from the event is used to inform the specification of service
	Patients	Feedback is arranged to the patient user group from the event and final specifications are discussed Specific patient groups with specific needs are targeted for feedback
EMPOWERMENT	Public	Members of the public who have previously been involved in the consultation are invited to view and test the new service – and give feedback in its early stages
	Patients	Two members of the patient group attend project guidance meetings to ensure that patient and public feedback is integral to the design and implementation of the service These members are also involved in site visits and other practical arrangements for the changes

A collaborative research proposal in cancer

INVOLVEMENT	Members of the public	The public may be appropriately involved if the research concerns the prevention of cancer and addressing lifestyle factors. Raising awareness of the need for the research project by distributing posters to hospitals
	Patients	Finding local support groups that might be interested in an exploratory meeting/workshop to outline the nature of the research and how current and past cancer patients can help
ENGAGEMENT	Members of the public	As below
	Patients	Working with patients' groups to: • Monitor and steer the project • Define the research question • Ask what outcomes should be measured in the study • Assess the viability of the research protocol • Assist with networking and information to engage/recruit patients to the study • Share the results with the study population
EMPOWERMENT	Members of the public	As below
	Patients	Members of patient groups may be recruited as co-researchers with roles such as: • Monitoring and steering the project • Helping with gathering data • Gathering data with support from other researchers • Analysing data with researchers • Providing commentary on outcomes and results • Helping with dissemination and translational aspects of research results.

Developing a patient information resource

INVOLVEMENT	Members of the public	A primary care provider wants to prepare a poster about the benefits of immunization to child health. They design three different posters and take them to a local mother and toddler club and ask the mothers which ones they are most likely to read. From the feedback they receive from the mothers they decide which poster is circulated
	Patients	An acute hospital wants to prepare a patient information leaflet on surgical procedures in weight loss surgery. They ask a senior clinician to write the leaflet and then show a draft to their hospital patient panel for comment
ENGAGEMENT	Members of the public	A primary care provider wants to prepare a poster about the benefits of immunization to child health. They know that within certain communities immunization rates are low. They approach a mother and toddler group within such a community and ask the mothers to help design the poster
	Patients	Senior clinicians (nurses and doctors) are aware that communicating the different surgical procedures available to weight loss surgery patients can be difficult. The clinicians consider developing visual aids to help the communication process and informed consent They contact patients who have undergone weight loss surgery and ask them to work with them, a medical designer and a patient advocate if needed, to produce visual aids
EMPOWERMENT	Members of the public	Mothers and health workers within a community with low immunization rates for childhood diseases are concerned at the impact on child health within the community The mothers and health workers approach their primary care provider and ask to work with them to design a social marketing campaign to increase immunization rates
	Patients	A weight loss surgery support group runs a blog for individuals who have either undergone weight loss surgery or who are considering it Individuals using the blog have commented on the lack of appropriate patient information available on different surgical weight loss methods. The support group decides to produce its own patient information DVD. They approach the weight loss surgeon at the acute trust, who agrees to work with them to produce the DVD The DVD is then used by the acute trust

A local public awareness campaign for flu

INVOLVEMENT	Members of the public	Finding out from the public what they need to know about flu, e.g. signs and symptoms, what to do, what not to do, how to communicate risk Testing these ideas with members of the public to gauge their reaction to and comprehension of the message
	Patients	This could be achieved in a focus group.Work with patient groups to alert those at extra risk from flu to ensure that those who need it are immunized quickly. An information meeting, with a panel comprising public members, public health communications experts, primary care, etc., to answer questions
ENGAGEMENT	Members of the public	After agreeing what we need to say and how we will say it, we return to our focus group to get feedback Identify cultural and communication barriers that might inhibit some people to seek immunization and/or treatment
	Patients	Community leaders and influencers may assist communication, especially in communities that are at risk, or for whom English may not be first language, and can help with both the suitability of written material and as local advocates. Develop relationships with patient organizations (of those patients identified as at risk) to use communication materials to best advantage
EMPOWERMENT	Members of the public	Return to community leaders or influencers after the crisis to assess how it was managed and what could be learnt from the experience This could take place in a meeting or focus group
	Patients	Monitoring input on at-risk patients being followed up for immunization and treatment After the 'crisis' period is over patients can be part of a review process – for lessons learned and how to improve response for next time

Commissioning a primary care service for mild to moderate depression

INVOLVEMENT	Members of the public	Information and invitations are sent by post to target groups who are known to suffer from mild to moderate depression via GP surgeries and primary health care centres
	Patients	Make contact with local mental health support groups to establish their interest in getting involved in the project Gathering existing evidence of service users' experiences of treatment and care for mild to moderate depression Gathering new data to reflect the gaps in existing evidence; via focus groups, surveys, discussion forum or visiting existing support group meetings and having a conversation Approach GP Patient Participation Groups to assess their experience of mild to moderate depression
ENGAGEMENT	Members of the public	Working with the public to understand and build into services the problems associated with mild to moderate depression that stop people seeking services, e.g. stigma and shame, etc. Working with other public service representatives on the role of other forms of treatment such as exercise, relaxation, etc., and how this can be reflected in commissioning Using local media to gather stories of treatment and care of mild to moderate depression
	Patients	Working with patient groups to develop and implement the gathering of new data on primary care services for mild to moderate depression and mapping it across the local area Analysis of data, feedback on data and implications for services, a workshop with service users, carers, primary care commissioners and mental health professionals participating. Work towards recommendations for commissioning services

EMPOWERMENT	Members of the public	As below
	Patients	Involvement in work to ensure that commissioning plans meet and reflect expected standards and guidance on mild to moderate depression Involved patients to be part of feedback loop on development of commissioning contract Review commissioning plans (as part of a working group or other) to ensure that the essence of patient feedback is still maintained in contracts Contributing to communication (leaflets, web page) that describes the changes to the services commissioned and what patients can expect to receive in treatment and care for mild to moderate depression Monitoring role – have the commissioned services helped those with mild to moderate depression?

Determining local health priorities

INVOLVEMENT	Members of the public	Seek the views about health priorities from a range of actual and potential service users Develop a panel of local people that can be communicated with face to face, by telephone, internet and post Consider a wider consultation strategy that reaches a significant proportion of the local population
	Patients	Identify local patient and support groups Approach them with the idea for developing health priorities and establish the best ways of communicating with them.
ENGAGEMENT	Members of the public	Hold open workshops, exhibitions and other events that help people explore, discuss and compare what matters to them in local service improvement Use voting methods or consensus development methods to help prioritize competing alternatives
	Patients	As above, but from a patient perspective
EMPOWERMENT	Members of the public	Public getting involved in actual commissioning decisions. Acting as advocates for priorities developed by the public. Usually entails reviewing existing priorities and government priorities, assessing available resources in light of local priorities. For those that participate in this more strategic work, there should be appropriate induction and support
	Patients	As above, but from a patient perspective

Further reading

Department of Health. *Equity and excellence: liberating the NHS*. London: Department of Health, 2010. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_117353.

🔑	key message
🔧	tool
✅	checklist
🤝	PPI examples and case studies
👁	PPI techniques
💭	PPI development methods
📄	summary