Patient and Public Involvement Toolkit

by Julia Cartwright, Sally Crowe

Edited by Carl Heneghan, Rafael Perera, Douglas Badenoch

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Contents

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Foreword

“Involve, Engage, Empower” – how often have we heard those words used In health care planning, only to find that they really mean nothing? This book Is the opposite of that. It dares the reader to mean business with patient involvement, engagement, and – most dangerous of all – empowerment. It leaves you with no excuse for not getting on with it, because everything you need is here, bar a tin of shoe polish.

The reason that Julia Cartwright writes with such clarity and authority is that she has actually made this happen. Uniquely, she brought together all the stakeholders in the locality where I practised as a GP for 31 years, and by a mixture of personal skill, energy and endless patience achieved agreement on issues which had plagued us for most of that period. Julia’s co-author, Sally Crowe, is helping to set the agenda for a genuinely patient-centred model of health care through her work with the James Lind Alliance, and its programme of identifying the research that is needed to support this.

When they tell you how to give a presentation, how to deal with unhelpful contributors, how to listen and how to react, do as they say: they know their business.

This is difficult work, and this book could not be more timely. General practitioners driven to despair by having to commission local care within a dwindling budget will find it full of advice on how to share such decisions meaningfully with local patients and politicians. The empowerment of patients is an inevitable part not just of current political rhetoric, but future reality.

User-driven health care is on the way: it challenges each one of us, either as a user or a professional, or both. This jargon-free book, with its excellent links, its clear analysis and its brilliantly practical approach is the best tool I know of to address this coming reality.

Richard Lehman

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20 Nov 2010

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 (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.