This book fills an important niche in the market providing practical expert advice on service user (patients, carers and the public) involvement in nursing and healthcare research. An invaluable guide for anyone working or involved in nursing and healthcare research, this book provides a step-by-step guide to the principles and process of involvement, including understanding the rationale for involvement, designing involvement, working with service users, and evaluating what has been achieved.

With illustrations, worked examples and tool sheets throughout, this evidence-based guide uses real life examples from recent research studies in health and social care research, thus relating theory to practice in a meaningful way. The Handbook of Service User Involvement in Nursing & Healthcare Research introduces a wide range of key issues, including:

- **Why?** Why should researchers involve service users?
- **How?** How can researchers and service users work together successfully and productively?
- **Who?** Who chooses to become involved in research? How are issues of representation and diversity addressed?
- **When?** At what stage should service users be involved in the research process?

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Handbook of Service User Involvement in Nursing and Healthcare Research
In memory of Ursula Hawgood, who worked with us, inspired us and involved us.
Handbook of Service User Involvement in Nursing and Healthcare Research

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The following people have kindly worked with us in the preparation of this book to share some of their experiences of service user involvement in research:

- **Sophie Auckland**, User Involvement Manager for Guy’s and St Thomas’ Foundation Trust and King’s College London Biomedical Research Centre explains her experiences of informing and advising academic and clinical research staff in a wide range of research areas including laboratory research, clinical trials and qualitative studies.
- **Sheila Donovan**, Research Fellow at the Faculty of Health and Social Care Sciences, Kingston University and St George’s University of London, explains some of the issues that can arise in relation to older service users’ views about payment.
- **Jennifer Laws**, a Researcher and Teaching Fellow at Durham University, provides an insight into managing diverse expectations whilst working with mental health service users to develop peer-support and advocacy services.
- **Professor Colin Torrance**, **Dr Keith Weeks** and **Christine Wilson** explain their views about embedding service user involvement in learning organisations. They are part of a research team at the University of Glamorgan, investigating the use of clinical simulation and virtual learning environments to educate healthcare professionals.
- **Hazel Thornton**, an Independent Advocate for Quality in Research and Healthcare, provides insights into service user involvement in clinical trials for breast cancer treatment.
- **Sally Crowe**, a consultant in Patient and Public Involvement, draws on her experiences of the practical and emotional aspects of involvement to provide advice about hearing the voices of those who are very sick.
- **Dr Patricia Grocott**, Reader Palliative Wound Care, King’s College London, and **Elizabeth Pillay**, Nurse Consultant, St Thomas’ Hospital London, explain how they are working in partnership with the charity DebRA UK to involve people with chronic and severe skin conditions in research.
- **Jennifer Newman**, Consumer Liaison Officer for the National Institute for Health Research Medicines for Children Research Network, explains her experiences of working to involve parents, carers, children and young people in the networks’ activities.
- **Professor Jane Coad**, based at Coventry University, explains some of her experiences of involving children and young people in the development of health services using participatory arts-based methods.
- **Amy Feltham** from YoungMinds provides a young person’s view of VIK (Very Important Kid) panel and explains how getting the little things right helps make sure the big things run smoothly.
• Julie Wray, Researcher/Healthcare Professional/Survivor, explains her views on embracing the patient/carer voice and the importance of caring for the person not the illness.

• Christine Wilson explains how she has developed interactive methods – a Living Library – to help engage healthcare professionals and researchers in dialogue with people with mental health problems.

• The Sunderland family from Northumberland provide an insight into the research they did with their father before his death to mesothelioma in 2009.

• Nazira Visram, an experienced patient representative and Macmillan Trainer, discusses ideas for moving forward and sustaining collective service user efforts alongside contributing to experiential learning and self-management programmes for cancer care.

• Rory Byrne, based at the University of Manchester, gives a user-researcher’s perspective of mental health service user involvement.

• Professor Jane Coad describes a collaborative project with the children’s charity CLIC Sargent and some of the lessons learnt about how to evaluate young people’s experiences of involvement.

• Antje Lindenmeyer, Senior Research Fellow, Warwick Diabetes Care Research and Education User Group, explains her experiences of assessing the benefits of service user involvement with lay people who have an active interest in the experiences and care of people living with diabetes.
About the authors

Dr Elizabeth Morrow I started working in healthcare research in 1999 when I took up a Research Assistant post at the Faculty of Health and Social Care Sciences based at St George’s Hospital and jointly run by Kingston University. Before that I trained as a geologist and had briefly worked for the National Trust showing visitors around Cornish engine houses. In my new career, working under the direction of Professor Fiona Ross, I began to learn about research with people, the health system and something about professional cultures. Over the years I have worked on nursing research studies and service development projects and have enjoyed building relationships with a wide range of service users and their representative organisations. In 2003, I was lead researcher on the National Institute for Health Research Service Delivery and Organisation PIN project (Patient and public involvement in nursing, midwifery and health visiting research), led by Professor Ross. My doctoral thesis went on to look at the development of service user involvement in health research in the United Kingdom and Australia. My thesis argued that current knowledge and conceptualisations of service user involvement in health research tend to underplay the significance of external influencing factors such as established notions of what constitutes health research. The research I undertook showed that although tensions about professional power over service user involvement in health research cannot be escaped, they can be better understood by examining the reasons behind resistance and discomfort. These reasons may be entirely valid, but where there is uncertainty there is also the potential to develop new knowledge through language development, new epistemological stances, and subjective experiences and views. I now work as a Research Fellow for the National Nursing Research Unit based at King’s College London. My research interests include exploring the contribution that service users can, and should, make to contemporary healthcare policy and practice. With Annette Boaz, Sally Brearley and other colleagues I teach service user involvement in research at King’s College London.

Dr Annette Boaz I have an ongoing interest in the roles patients, carers and the public play in research and I am currently a Lecturer in Translational Research at King’s College London. I am leading a project exploring the relationship between public and patient involvement in research and public engagement in science. I am also supporting biomedical researchers with an interest in service user involvement in their research. I have previously worked at the universities of Oxford and Warwick, carrying out research in a wide variety of policy areas, completing evaluations for the UK Cabinet Office and Home Office. I also worked briefly in the Policy Research Programme at the UK
About the authors

Sally Brearley  I trained and worked as a physiotherapist in Manchester in the 1970s. In the mid-1980s, I gained a BSc in Nursing Studies at King’s College London. For my final year’s dissertation I reviewed research on what was then called patient participation. During my time at King’s College London, Fiona Ross was a lecturer there. After an MA in Social Anthropology, and whilst my children were small, I became interested in patient stories and got involved in a number of patient organisations. Meeting up again with Fiona Ross and with Elizabeth Morrow, both then at the Faculty of Health and Social Care Sciences Kingston University and St George’s University of London, we began our collaboration on service user involvement in research, which has now spanned more than a decade. Currently I am an honorary fellow at the Faculty of Health and Social Care Sciences Kingston University and St George’s University of London, and at the National Nursing Research Unit, King’s College London. I am still active in a number of organisations representing patients and the public, and in supporting the National Health Service.

Prof Fiona Ross   I did my first degree at Edinburgh University, where I trained to be a nurse. After qualification I worked as a district nurse in London where I enjoyed the privilege of looking after people in their own homes, where they could choose how and in what way they received their care. Perhaps it was these beginnings that led me to a PhD that focused on patient-held information, in relation to medication management. Later research opportunities built my interest in how to better work with patients in the co-production of research. I believe research should not be the preserve of the professional, but should be done with, and on account of, the people, patients and their families, whom it should ultimately benefit. This book is the outcome of some of that thinking, produced by a talented and collaborative group of researchers, whom I have been privileged to work with. Along the way I have done a number of jobs and held Chairs in Primary Care Nursing, been the Director of the National Nursing Research Unit at King’s College London, and I am currently the Dean of a large Faculty of Health and Social Care Sciences, run as a joint venture by Kingston University and St George’s, University of London.

Department of Health. At Warwick, I was involved in the evaluation of the Better Government for Older People action research programme, working alongside a group of older people committed to improving services for an ageing population.
Preface

In nursing and healthcare practice, there is a long history of working with patients to understand their health needs and to assess the best options for treatment and care. Nurses and other healthcare practitioners – including midwives, health visitors, occupational health workers, community health workers, or another person trained and knowledgeable in nursing or other allied health professions or public/community health – have tended to make the most of this close relationship with the patient, to try to see things from the patient’s perspective.

As we see it, nursing and healthcare research is about the generation of knowledge to inform practice, education, management and policy development that relates to these professional roles. It can be undertaken by paid and unpaid researchers from many different clinical and non-clinical backgrounds, as well as in education, management, policy development and student research projects. In recent years, across many countries, there have been widespread changes in research policy and practice which aim to involve ‘service users’ (patients, carers and the public) more directly and actively in all aspects of health and social care research. In health policy and research literatures the term ‘service user’ is generally used to mean patients, carers and members of the public; however, alternative terms such as ‘patient’, ‘public’, ‘consumer’, ‘citizen’, ‘lay representative’ and ‘user representative’ are also in use. However, the language of involvement is continuously developing and is contested.

This book looks at service user involvement at a time when political and professional support is growing rapidly as part of a trend towards improving public engagement in governance of public institutions. Changes are being seen to involve the public in the organisation and delivery of healthcare services, the education of healthcare professionals, and in all aspects of health and social care research. These changes place new emphasis on gaining a balance between developing valid generalisable knowledge and benefiting the community that is being researched.

Recent politically driven forms of involvement are distinctly different from longer-standing emancipatory movements where people who are directly affected by the issues seek to bring about change. Growing numbers of service users are embarking on their own personal health research, as well as ‘user-led’, ‘user-controlled’ and ‘survivor’ research. Research commissioners are also more open to funding user-led research and the leadership role of service users is beginning to be recognised.

Increasingly, demonstrating a commitment to working with service users is a condition of being awarded research funding, but it is also becoming a sign of quality in research. There is some evidence that involving service users at different stages of the research process can help to improve research studies in terms of the questions they seek to
address, how they are carried out and the impact of the findings. There is stronger evidence that service user involvement has an impact on the service users and researchers who are involved in the process.

At the outset, the realities of involving service users in research can be daunting for new and experienced researchers. Service users may also be apprehensive or have uncertainties about what the process will entail. Nurses and other healthcare professionals often need to combine their research role with their clinical roles and this duality is a potential cause of ambiguity and tension when inviting service users to work alongside them as partners. Knowing who to involve and how to involve different people requires sensitivity and understanding, as well as an appreciation of how research can be perceived as being remote from the ‘real world’. Researchers need to be aware of processes of negotiation, mutuality and respect in their work with service users. There are specific types of ethical and legal issues that differ from involving people as subjects in research. There are research governance, management and resource issues that mean that researchers need to be able to plan and record service user involvement activities. Researchers can make use of models of service user involvement and techniques to enable service users’ ideas to be brought forward and made use of in research.

This book is an introduction to service user involvement in research which will be useful for anyone working in, or learning about, nursing or healthcare research. We have purposely used the term ‘research teams’ in the book to convey the fact that researchers do not work in isolation, and, that the ideal situation is for researchers and service users to learn about service user involvement in research together.

The book provides some insight into service users’ diverse expectations about involvement, the types of contributions they might make, and the impact their involvement is likely to have. The key ideas and tools included through the book could be useful for established healthcare researchers to support service user involvement in research design, writing proposals for research funding and working to embed learning across research organisations. It focuses on service user involvement in UK and European contexts but readers from other countries are likely to recognise the issues and be able to make use of many of the ideas that are put forward.

The idea for the book came from a series of studies and collaborations between the authors. In 2003, three of the authors were involved in a scoping study commissioned by the National Co-ordinating Centre for Service Delivery and Organisation Research and Development Nursing and Midwifery Subgroup (Ross et al. 2004). The overall aim of the scoping study was to identify priorities for research funding in nursing and midwifery in England by reviewing the literature, consulting professionals and stakeholders, and conducting discussions with consumer representatives. Involvement of members of 38 Community Health Councils during the scoping exercise had a significant influence on the depth of information we gained and proved to us that involvement was achievable and that it added value to research (Smith et al. 2005). In 2004, we were commissioned to undertake the National Institute for Health Research Service Delivery and Organisation PIN project (Patient and public involvement in nursing, midwifery and health visiting research). This study again involved service users, but more actively in the review process itself. Between us, our collective experiences gave us confidence to aim for more substantial service user involvement as part of a collaborative multi-method approach (Smith et al. 2008).
Through these and other studies, we have learnt about the practical aspects of service user involvement, such as the need to meet people on their own terms, how to build relationships through personalised communication and understanding that every service user has a unique contribution to make. Working with service users helped us to overcome some of our own apprehensions about involvement and to find better ways to work in partnership. Of course, we have also been informed, influenced and inspired by the work of other researchers and service users, and what is written in the research literature. We have taken this learning forward in our own work and contributed to developing guidelines on service user involvement for nurse researchers (Royal College of Nursing 2007).

Our intention for this book is to share some of this learning in a useful handbook. We would not wish for it to be seen as a set of instructions. We see it as a collection of ideas and tools to help inform the design and undertaking of service user involvement in nursing and healthcare research. It is a resource for anyone who wants to find out more or to make connections with individuals and organisations who are leading the way in developing service user involvement. Through the book, you will find case studies written by service users and researchers, and from further afield in health and social care. These contributions help to bring the topic of service user involvement in research to life and to highlight key issues from the perspectives of those who have experienced service user involvement.

References


Structure of the book

We have divided the book into three main parts: Part I (Preparing), Part II (Learning) and Part III (Evaluating). Each chapter begins with a summary of key issues covered in the chapter and ends with key principles for practice. We have used figures and summary boxes throughout to make the material accessible for reference purposes and for teaching and learning.

Part I  Preparing

Part I begins by introducing the concept of service user involvement in nursing and healthcare research and explaining some of the different ways of approaching the topic. It then sets out some of the political and research contexts of involvement and moves to engage the public more actively in a wide range of professional areas of working. We then look at some of the underlying drivers for service user involvement and the perspectives different stakeholders might have of the issues. We outline what is currently known about impact and some of the challenges associated with building knowledge to inform research practice, such as focusing research efforts and sharing existing learning. Chapter 2 concerns concepts of involvement, including the concepts of ‘service users’, ‘involvement’, ‘representation’, ‘experiential knowledge’, ‘empowerment’ and ‘participation’. We look at the models that authors have devised to help explain the types of relationships that can exist between service users and researchers in research. These include a ladder of participation, levels of involvement (consultation, collaboration, control) and a continuum of participation. We present our own broad theoretical framework for approaching service user involvement at the end of Chapter 2. It sets out four interrelated components for personal and professional learning: context, methods, roles and outcomes. Chapter 3 moves on to discuss how to design involvement, including practical advice about deciding who to involve; building in opportunities and time for involvement, costing and payments; and research ethics and governance issues to be aware of. The final chapter of the part (Chapter 4) presents ideas for establishing good working relationships including making connections with service users, developing working environments, being clear about roles and responsibilities, explaining legal and ethical issues, providing training and support, effective communication, and opportunities for feedback and reflection. We look at some of the issues associated with embedding service user involvement in research organisations, how organisations can spread learning, build expertise and develop best practice for ways of working and support systems.
Part II Learning

Part II focuses on involving and learning from different types of service users. It begins by looking at issues of involving patients and clients who are receiving health care, and people who are very sick or have rare clinical conditions (Chapter 5). Involvement over the life course is an important issue and some of the more specific issues of involving children, young people, adults and older people are outlined in Chapter 6. Chapter 7 discusses the multiple barriers and circumstances that affect seldom-heard groups including lack of awareness, communication barriers and access issues. It sets out some key issues in relation to involving people with physical disabilities, the deaf and people who are hard of hearing, people who are blind or partially sighted, people with learning disabilities, people with degenerative cognitive impairment, people with mental health problems, and Black and minority ethnic groups. Chapter 8 focuses on service user-led research. It explains how individual service users, sometimes with the support of their family members or carers, may undertake their own research to better understand an illness or the options for treatment or care. We then look at the types of research work that volunteer networks, service user-led organisations, charities and not-for-profit organisations might undertake or be involved in, and the emerging roles of experienced service user representatives and academic service user researchers.

Part III Evaluating

Part III focuses broadly on issues of evaluating service user involvement. Chapter 9 begins by looking at known indicators of success which research teams can use to plan and assess whether they are meeting established ideas of good practice. The chapter then explains why it is important to document service user involvement work as part of recording research processes and demonstrating active and direct participation of service users. Research teams can also make use of a range of reflective techniques to examine issues about the quality of involvement processes, for example reflective diaries, feedback and evaluation forms, and reflective interviewing. By using reflexivity and considering quality at an organisational and research systems level, research teams may also be able to contribute towards more supportive research environments and to challenge any barriers to involvement. Chapter 10 focuses on issues of impact, including suggestions on how to recognise impact, record impact and report impact. Understanding impact is important because it can help to show whether involvement is effective and to demonstrate the benefits and drawbacks in different research contexts. Chapter 11 takes a different look at the issues by examining international developments in service user involvement in research across Europe, USA, Canada, Australia and New Zealand, and in developing countries. Different countries tend to favour different types of concepts which may be related to service user involvement, for example patient-centred care, consumer engagement, patient participation, or patient and public involvement. The chapter provides details of government-funded and non-government-funded organisations which provide information, funding and support for service user involvement activities internationally.
Chapter 12 brings a close to the book by presenting summary conclusions and looking at some of the wider implications of service user involvement for enhancing evidence-based practice and enriching healthcare professional education. For those readers who are also teachers, the chapters of this book could be used as an outline curriculum for a session or module on service user involvement in nursing or healthcare research. Example topics for student discussions, group work and essay questions are provided. The final sections of the chapter look at the issues of service user involvement in relation to developing professional roles and securing service users’ commitment to involvement.
This book was informed and inspired by the aforementioned contributors and many other researchers and service users who we have had the pleasure of working with. We would like to personally acknowledge the following people: Dr Patricia Grocott, Reader at the Florence Nightingale School of Nursing and Midwifery, King’s College London, and Professor Margaret O’Connor at the School of Nursing and Midwifery, Monash University, for their support and advice on work which led to this book. Dr Janette Bennett provided advice on concepts of knowledge and power.

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Thank you to the many service users who have given their time and inspired us in various ways. In particular, we would like to acknowledge the contribution of members of the service user reference group who worked with us on the National Institute for Health Research Service Delivery and Organisation PIN project (Patient and public involvement in nursing, midwifery and health visiting research). Thanks to them and their organisations: Age Concern; AIMS (Association for Improvements in the Maternity Services); BLISS – The premature baby charity; British Council for Disabled People; British Heart Foundation; Cancer Research UK; Carers London/UK; Clifford Beers Foundation; Diabetes UK; Redbridge Primary Care Trust; Voluntary Groups Advisory Council Diabetes UK; Friends of the Elderly; Folk.US; London Voices & Croydon Voices; National Children’s Bureau; National Childbirth Trust; Northumberland User Voice; Patient and Public Involvement Forum Royal College of General Practitioners; Quality Research in Dementia; Shaping our Lives; and Values into Action. Guest advisors to the group were Mr Tim Twelvetree, Institute for Public Health Research and Policy, and Ms Jayne Pyper, Ovacome.
Part I

Preparing
Chapter 1
Perspectives and expectations

Key summary points

- **Approaching service user involvement**: Service user involvement in research means different things to different people, however, the term is generally used to mean the active and direct participation of service users in the commissioning, design, undertaking or evaluation of research. Approaching service user involvement requires asking questions including: Why should researchers involve service users? What are the purposes and the benefits? How can the process be successful and productive? Who should be involved to ensure representation and diversity? When should service users be involved and at which stages of the research?

- **Political and research contexts of involvement**: Across many Westernised nations there is strong interest in engaging the public more actively in a wide-range of professional areas of working, including healthcare delivery, service design and health and social care research. Diversity is an important concept in relation to both the contexts of service user involvement and to the professionals and service users it concerns. At the same time many of the challenges and opportunities of service user involvement are shared between professional groups and across disciplinary boundaries.

- **Historical roots and social movements**: It is important to appreciate that moves to involve service users in a wide-range of professional activities have come about because of the culmination of a series of historical events, rather than a one-off policy directive. The drivers for service user involvement include historical and ethical reasons such as challenges to medical authority, changing roles of patients in policy, user-led research, democratisation of public services and public response to professional scandals.

- **Perspectives of service user involvement**: In general, research funders are looking for a commitment to service user involvement including making sure it is appropriate to the research and that there is adequate planning and budgeting. Researchers may hope that involving service users will help them to secure funding and to improve the quality and outcomes of the research they undertake. Service users have a wide range of personal motives for wanting to be involved in research. As a minimum they should be given sufficient information about their involvement in the research, to be respected, to be involved in ways that suit them, and to be acknowledged for their contributions to the research.