

Reading list

Public involvement in health services

August 2015

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BOOKS/REPORTS

Wallis, Ed and Pearson, Amy, editors
Fabian Society

The local health service? : how to balance local control and national standards in access to health care.

London : Fabian Society, 2015

Web publication

This collection of essays examines how to balance local control and national standards in access to health care. It also considers how greater control for services users, employees and local leaders can be delivered alongside higher performance and value for money.

http://www.fabians.org.uk/wp-content/uploads/2015/07/FABJ3462_Health_Service_WEB_SPREADS2.pdf

Healthwatch Islington

Experiences of integrated care and the Integrated Care Ageing Team.

London : Healthwatch Islington, 2015

Web publication

Healthwatch Islington was commissioned by Islington CCG to carry out engagement and interviews with residents, relatives/carers and staff in local care homes. The aim of the research was to find out about users experiences of the Integrated Care Ageing Team service and how residents (and where appropriate relatives/carers) had been involved in their treatment, and in conversations about their end of life care.

http://www.healthwatchislington.co.uk/sites/default/files/the_integrated_care_ageing_team_service_2015.pdf

Associated documentation: <http://www.healthwatchislington.co.uk/resources/reports>

Muir, Rick and Quilter-Pinner, Harry
Institute for Public Policy Research

Powerful people : reinforcing the power of citizens and communities in health and care.

Report ; July 2015

London : IPPR, 2015

Web publication

This report argues for giving citizens greater control over their own health and care, so that services are redesigned around their needs and aspirations, to improve health outcomes, and to save money by supporting people better to manage their conditions themselves.

http://www.ippr.org/files/publications/pdf/powerful-people_July2015.pdf?noredirect=1

Associated documentation:

<http://www.ippr.org/publications/powerful-people-reinforcing-the-power-of-citizens-and-communities-in-health-and-care>

Gilburt, Helen, et al.
The King's Fund

Local healthwatch : progress and promise.

London : [DH], 2015

Web publication

Local Healthwatch organisations are the local champion for patients, services users and the public, covering both health and social care. The Department of Health commissioned The King's Fund to review the progress made by local Healthwatch. This report identifies the positive steps that could be taken across the system to enable a high-performing and effective local Healthwatch network. This report was commissioned by the Department of Health. However, it is based on independent research conducted by The King's Fund and the conclusions reached are those of the authors.

<https://www.gov.uk/government/publications/local-healthwatch-progress-and-promise>

Faulkner, Alison, et al.

National Involvement Partnership and National Survivor User Network
Involvement for influence : 4Pi national involvement standards.

London : NSUN, 2015

Web publication

The National Involvement Partnership (NIP) project has been funded by the Department of Health IESD voluntary sector funding. The aim of the three year project was to strengthen involvement in the planning, delivery and evaluation of the services and support we use for our mental health and wellbeing needs. Some basic principles have been established to encourage people to think of involvement in terms of principles, purpose, presence, process and impact (4Pi). This report sets out its main tasks as developing national involvement standards in mental health and hard-wiring involvement into the planning, delivery and evaluation of mental health services.

<http://www.nsun.org.uk/assets/downloadableFiles/4PiNationalInvolvementStandardsFullReport20152.pdf>

Associated documentation:

<http://www.nsun.org.uk/about-us/our-work/national-involvement-partnership/>

Nicholas, Lydia and Broadbent, Stefana

National Voices

Collective intelligence in patient organisations.

London : National Voices, 2015

Web publication

This report looks at the often unsung but increasingly important work of patient organisations as knowledge brokers. Patient organisations have played a significant role in networks of health and social care for almost a century. Much of this work has been highly visible; they act as public voices for patients, fundraise, research, campaign, educate, advocate, and provide support services. But we argue that their participation in knowledge work is critical and over coming decades will become one of the most important ways they will advance the interests of patients. As collectives with varied members and activities patient organisations are uniquely capable of building relationships across sectors and cultures, easing the flow of information throughout the network, enhancing its capacity to gather and distribute information and to produce new insights. This can enhance individual participants' knowledge and effectiveness and the collective intelligence of the entire healthcare system.

http://www.nesta.org.uk/sites/default/files/collective_intelligence_in_patient_organisations.pdf

Associated documentation:

<http://www.nesta.org.uk/publications/collective-intelligence-patient-organisations>

Public Health England and NHS England

A guide to community-centred approaches for health and wellbeing : briefing.

London : PHE, 2015

Web publication

The move to a new health system has created opportunities for public health and healthcare to become more person and community centred. Changes in commissioning and practice need to be supported by good access to evidence and practical information. This briefing gives an overview of the case for change, key concepts and types of community-centred approaches.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/402889/A_guide_to_community-centred_approaches_for_health_and_wellbeing_briefi_.pdf

Ruane, Sally

Democratic Audit and Centre for Health and the Public Interest

Democratic engagement in the local NHS.

[London] : Democratic Audit, 2014

Web publication

This essay looks at the recent history of patient and public involvement in the NHS, and those elements of the health system lying outside the NHS. It identifies the barriers to democratic engagement and sets out ways in which accountability can be strengthened, particularly through Healthwatch and local authorities.

<http://chpi.org.uk/wp-content/uploads/2014/04/Democratic-engagement-in-the-local-NHS-Sally-Ruane.pdf>

Boardman, Jed and Roberts, Glenn
Centre for Mental Health and NHS Confederation. Mental Health Network

Risk, safety and recovery.

Implementing Recovery through Organisational Change (ImROC)

briefing ; 9 (June 2014)

London : CMH, 2014

Web publication

This briefing paper finds that mental health services can manage risk more effectively by involving service users in planning for safety. It argues that risk and safety are rightly major concerns in mental health care but that traditional methods of assessing risk have stood in the way of helping people to recover their lives. It argues that jointly produced 'safety plans' can be more effective ways of managing risk as well as enabling people to get on with their lives.

<http://www.centreformentalhealth.org.uk/Handlers/Download.ashx?IDMF=6461ca23-6a96-493b-a7c4-0411892ca6ef>

Associated documentation:

<http://www.centreformentalhealth.org.uk/pdfs/ImROC-Briefing-Risk-Safety-and-Recovery.pdf>

Donetto, Sara, et al.

King's College London. National Nursing Research Unit

Using experience-based co-design (EBCD) to improve the quality of healthcare : mapping where we are now and establishing future directions : final report.

London : King's College London, 2014

Web publication

This report provides something of a stock-take of the 'state of the art' of EBCD, summarising the findings from a recent survey the NNRU have undertaken of those leading and involved in projects worldwide.

<http://www.kcl.ac.uk/nursing/research/nuru/publications/Reports/EBCD-Where-are-we-now-Report.pdf>

Adams, Mary, et al.

King's College London. National Nursing Research Unit

Improving patient-centred care through Experience-based Co-design (EBCD) : an evaluation of the sustainability and spread of EBCD in a cancer centre : final executive report.

London : King's College London, 2014

Web publication

A cancer centre was formed across two large NHS trusts in 2006 with the aspiration of delivering internationally renowned cancer services - in the 'top 10 globally' - for patients in the region. In 2008 the centre began an action research project encompassing several work streams (such as the engagement and training of senior managers) to implement patient centred care (PCC). This evaluation was conducted between July 2011 and July 2012. This evaluation was commissioned to specifically examine the sustainability and spread of the chosen quality improvement approach: Experience-based Co-design (EBCD). EBCD is a form of participatory action research involving a six-stage design process that seeks to harness and use subjective experiences of providing and receiving health care services in order to prioritise and implement quality improvements.

<http://www.kcl.ac.uk/nursing/research/nuru/publications/Reports/Improving-PCC-through-EBCD-Report.pdf>

ISBN: 9781909029316

West, Michael, et al.

The King's Fund

Developing collective leadership for health care.

London : The King's Fund, 2014

Web publication

This paper argues that collective leadership - as opposed to command-and-control structures - provides the optimum basis for caring cultures. Collective leadership entails distributing and allocating leadership power to wherever expertise, capability and motivation sit within organisations. NHS boards bear ultimate responsibility for developing strategies for coherent, effective and forward-looking collective leadership.

http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/developing-collective-leadership-kingsfund-may14.pdf

Associated documentation:

<http://www.kingsfund.org.uk/publications/developing-collective-leadership-health-care>

National Institute for Health Research. INVOLVE

Senior investigators : leaders for patient and public involvement in research.

Eastleigh : INVOLVE, 2014

Web publication

This publication highlights the experiences of five National Institute of Health Research (NIHR) senior investigators who have participated with the public and patients in their research. It outlines the benefits in patient and public involvement in research for both researchers and participants.

<http://www.invo.org.uk/wp-content/uploads/2014/07/NIHRSeniorInvestigatorsINVOLVE2014.pdf>

NHS England

Principles for participation in commissioning.

Bite-size guides to patient and public participation ; Guide 1

London : NHS England, 2014

Web publication

This is one of four guides developed by NHS England with partners and by reviewing good practice in each area: principles for participation in commissioning; governance for participation; planning for participation; and budgeting for participation. They aim to support CCGs and others to plan and deliver good patient and public participation.

<http://www.england.nhs.uk/wp-content/uploads/2014/03/bs-guide-princ-part.pdf>

Associated documentation:

<http://www.england.nhs.uk/2014/03/13/pat-pub-participation/>

NHS England

Governance for participation.

Bite-size guides to patient and public participation ; Guide 2

London : NHS England, 2014

Web publication

<http://www.england.nhs.uk/wp-content/uploads/2014/03/bs-guide-govern-part.pdf>

NHS England

Planning for participation.

Bite-size guides to patient and public participation ; Guide 3

London : NHS England, 2014

Web publication

<http://www.england.nhs.uk/wp-content/uploads/2014/03/bs-guide-plann-part1.pdf>

NHS England

Budgeting for participation.

Bite-size guides to patient and public participation ; Guide 4

London : NHS England, 2014

Web publication

<http://www.england.nhs.uk/wp-content/uploads/2014/03/bs-guide-budget-part.pdf>

Smith, Lucy

Office for Public Management

Revolutionising the NHS with patient power.

OPM Policy Paper ; 15.05.2014

London : OPM, 2014

Web publication

This paper highlights how patient power can be used to transform all levels of the health service - from shaping policy and system reforms, effecting service delivery changes, to transforming the dynamic between patients and their healthcare providers. In it we draw on OPM's own experiences, as well as good practice examples from a recent OPM-hosted seminar, and consider how the health service can put the needs and wants of patients at the heart of everything it does through effective patient and public involvement.

<http://www.opm.co.uk/wp-content/uploads/2014/05/Revolutionising-the-NHS-with-Patient-Power.pdf>

Compact Voice

Independence of local Healthwatch.

[London] : Compact Voice, 2013

Web publication

This paper outlines methods available to local Healthwatch to help maintain independence.

http://www.healthwatch.co.uk/sites/default/files/170513maintaining_independence.pdf

British Medical Association

Local accountability.

Understanding the reforms ; (April 2013)

London : BMA, 2013

Web publication

This briefing paper examines the new structures for local accountability within the NHS and the new broader role for local authorities. These changes form part of the Government's NHS reform agenda which was legislated for by the Health and Social Care Act 2012.1 The NHS reforms in England introduced four new functions for local authorities as highlighted in the box below; the first three are discussed in this paper.

<http://bma.org.uk/->

[/media/Files/PDFs/Working%20for%20change/Shaping%20healthcare/Understanding%20the%20NHS%20reforms/understandnhsreforms_localaccountability_apr2013.pdf](http://bma.org.uk/media/Files/PDFs/Working%20for%20change/Shaping%20healthcare/Understanding%20the%20NHS%20reforms/understandnhsreforms_localaccountability_apr2013.pdf)

Associated documentation:

<http://bma.org.uk/working-for-change/doctors-in-the-nhs/nhs-structure-new/understanding-the-reforms>

The Health Foundation

Involving people in safety : a summary of learning from a Health Foundation roundtable.

Event report ; June 2013.

London : The Health Foundation, 2013

Web publication

On 1 May 2013 the Health Foundation hosted a roundtable event to explore how the public, patients, their families and carers can be involved in improving patient safety.

<http://www.health.org.uk/publications/involving-people-in-safety/>

ISBN: 9781909029088.

The King's Fund

Patient-centred leadership : rediscovering our purpose.

London : The King's Fund, 2013

Web publication

This report summarises the main findings of the Francis Inquiry into the failings of care at Mid Staffordshire in relation to NHS leadership and culture. It sets out what needs to be done to avoid similar failures in future, focusing on the role of three key 'lines of defence' against poor-quality care: frontline clinical teams, the boards leading NHS organisations, and national organisations responsible for overseeing the commissioning, regulation and provision of care. It recommends that patient leaders should work alongside NHS leaders to support the transformation called for in the Francis Inquiry report.

http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/developing-collective-leadership-kingsfund-may14.pdf

Local Government Association

Knowledge and skills and competencies for an effective local Healthwatch.

Health, adult social care and ageing.

London : LGA, 2013

Web publication

This document sets out an initial view of what the key knowledge, skills and competencies of an effective local Healthwatch would include.

http://www.local.gov.uk/c/document_library/get_file?uuid=84f78a86-71f3-4abe-94cd-fc81ca7ef3f8&groupId=10180

Local Government Association

Developing effective local Healthwatch : key success features..

London : LGA, 2013

Web publication

It is hoped that this document will help councils to better understand the commissioning of local Healthwatch and review how well their local Healthwatch delivers its roles and responsibilities. It can also help local Healthwatch develop their understanding of what is expected of them and how they can deliver best practice.

<http://www.local.gov.uk/documents/10180/11463/Delivering+effective+local+Healthwatch+-+key+success+factors/0aa41576-d5f1-40e9-9b7c-fa2d9716618e>

Local Government Association and Great Britain. Department of Health

Local Healthwatch regulations explained : lay and volunteer involvement and restrictions on activities of a political nature : Part 6 of the NHS Bodies and Local Authorities (Partnership Arrangements, Care Trusts, Public Health and Local Healthwatch) Regulations 2012.

London : Local Government Association, 2013

Web publication

There has been some debate about the interpretation of the local Healthwatch regulations. By their nature regulations are technical, using legal phrasing and wording which is often more precise than the common usage of language. This note aims to explain and provide clarity in relation to the following issues: (a) lay person and volunteer involvement in local Healthwatch and; (b) restrictions on activities of a political nature. This is not intended to be a substitute for or a definitive way of applying the regulations. Only the courts can provide a definitive interpretation of the legislation, and if there are any doubts, legal advice should be sought

http://www.local.gov.uk/c/document_library/get_file?uuid=0a4e69a3-2d07-41d2-896d-0477fde029dc&groupId=10180

National Voices

Evaluation of the Pilot Patient Leadership Programme.

London : National Voices, 2013

Web publication

The pioneer Patient Leadership Programme took place January to June 2013. Of 17 people who started the programme, 14 completed it. The feedback from those who completed the programme has been very positive. Of the three that were unable to finish, in two cases this was related to health reasons, in the third case we have been unable to get a clear reason. The formal evaluation has so far has taken the form of a compilation of written feedback given after each session, compiled by the Centre for Patient Leadership.

http://www.nationalvoices.org.uk/sites/www.nationalvoices.org.uk/files/patient_leadership_briefing_note_0.pdf

National Voices

Patient leadership : the start of a new conversation.

London : National Voices, [2013]

In order to recognise patients' new roles, give them greater status, and make the argument for proper support and development for the people who get engaged, it seems useful to start a new conversation - to discuss the idea of 'patient leadership'.

http://www.nationalvoices.org.uk/sites/www.nationalvoices.org.uk/files/patient_leadership_briefing_note_0.pdf

Hampson, Martha, et al.

Nesta

By us, for us : the power of co-design and co-delivery.

People Powered Health

London : Nesta, 2013

Web publication

At the core of the People Powered Health approach is collective ownership of health and wellbeing. Creating a health system driven by the people within it, not by the institutions that provide care, requires a focus on the interactions between people and providers at all stages; in designing, delivering, using, and evaluating services. This report examines the benefits of designing and delivering health services in conjunction with patients and service users.

http://www.nesta.org.uk/sites/default/files/the_power_of_co-design_and_co-delivery.pdf

Associated documentation:

<http://www.nesta.org.uk/project/people-powered-health>

NHS England

Transforming participation in health and care : 'the NHS belongs to us all'.

[Leeds] : NHS England, 2013

Web publication

This guidance aims to support commissioners to improve individual and public participation and to better understand and respond to the needs of the communities they serve.

<http://www.england.nhs.uk/wp-content/uploads/2013/09/trans-part-hc-guid1.pdf>

Rouse, Jenny

New Economics Foundation

Leadership for Empowered and Health Communities programme evaluation.

London : NEF Consulting, 2013

Web publication

The Leadership for Empowered and Healthy Communities programme was a course consisting of five day-long sessions, run over a period of six months. It was developed from a recognition that if services are to be designed and delivered in partnership with communities, there needs to be understanding, drive and passion for the approach amongst leaders in health and social care. This evaluation intends to: provide a concise and unbiased appraisal of how the course and its philosophy were perceived by participants; identify any tangible impacts on participants and their peers resulting from attending the course; and make recommendations based on the evaluation findings.

http://www.thinklocalactpersonal.org.uk/library/nef_consulting_leadership_evaluation_final.pdf

Associated documentation:

<http://www.thinklocalactpersonal.org.uk/BCC/Latest/resourceOverview/?cid=9475>

ISBN: 9780101861021

Great Britain. Parliament. Department for Communities and Local Government

Local Government and Public Involvement in Health Act 2007 : post legislative scrutiny memorandum.

HC ; 8610

London : Stationary Office, 2013

Web publication

This memorandum has been prepared by the Department for Communities and Local Government with contributions from Department of Health and Wales Office for submission to the Communities and Local Government Committee ("the Committee"). It is published as part of the post-legislative scrutiny process. It provides the Committee with the Departments' post-legislative assessment of the Local Government and Public Involvement in Health Act 2007.

<http://www.official-documents.gov.uk/document/cm86/8610/8610.pdf>

Local Government and Public Involvement in Health Act 2007:

<http://www.legislation.gov.uk/ukpga/2007/28/contents>

Primary Care Commissioning

Embedding patient and public engagement : a report on learning from interviews with CCG leaders.

[Leeds] : PCC, 2013

Web publication

This report of a survey of clinical commissioning group leaders, conducted in October and November 2012, provides a snapshot of attitudes to and readiness for effective engagement with patients and the public.

[http://www.networks.nhs.uk/nhs-](http://www.networks.nhs.uk/nhs-networks/documents/documents/ppe/FINAL%20Embedding%20patient%20and%20public%20engagement.pdf)

[networks/documents/documents/ppe/FINAL%20Embedding%20patient%20and%20public%20engagement.pdf](http://www.networks.nhs.uk/nhs-networks/documents/documents/ppe/FINAL%20Embedding%20patient%20and%20public%20engagement.pdf)

Summary report:

<http://www.networks.nhs.uk/nhs-networks/documents/documents/ppe/FINAL%20-summary-%20Embedding%20patient%20and%20public%20engagement.pdf>

Regional Voices, et al.

Learning from the LINKs : leadership and governance.

[Leeds] : Regional Voices, 2013

Web publication

This document is part of a suite of four resources, which reflect on how LINKs have developed and delivered leadership and governance, gathered, captured and used public views from engagement activities, right through to representing these views and influencing decision-making.

<http://www.linkstogoodpractice.org.uk/sites/default/files/editor/Leadership.pdf>

Regional Voices, et al.

Learning from the LINKs : engagement.

[Leeds] : Regional Voices, 2013

Web publication

<http://www.linkstogoodpractice.org.uk/sites/default/files/editor/Engagement.pdf>

Regional Voices, et al.

Learning from the LINKs : representation.

[Leeds] : Regional Voices, 2013

Web publication

<http://www.linkstogoodpractice.org.uk/sites/default/files/editor/Representation.pdf>

Regional Voices, et al.

Learning from the LINKs : influence.

[Leeds] : Regional Voices, 2013

Web publication

<http://www.linkstogoodpractice.org.uk/sites/default/files/editor/Representation.pdf>

Edgman-Levitan, Susan, et al.

World Innovation Summit for Health. Patient and Family Engagement Working Group.

Partnering with patients, families, and communities for health : a global imperative.

[Doha] : WISH, 2013

This report introduces the Global Health Partnership Framework and describes opportunities for involving people in healthcare. The report argues that engagement is an essential tool for improving global health, as it promotes stewardship and utilisation of limited resources.

<http://www.wish-qatar.org/app/media/387>

Associated documentation:

<https://www.imperial.ac.uk/global-health-innovation/our-research/our-publications/wish-reports-2013/>

Cooke, Sally

Compact Voice

Informing and influencing the new local health landscape : a guide for local Compacts.

[London] : Compact Voice, 2012

Web publication

This guide gives an overview of the new health landscape and ways in which voluntary organisations can get involved and influence the development of their local Compacts. In particular, it: provides information about the key elements of local health reform, and explains how the new and emerging health landscape will affect local Compact partnerships; outlines how local Compacts can influence the development of local health partnerships and structures; and discusses who local Compact partnerships should be communicating with and how.

http://www.compactvoice.org.uk/sites/default/files/compact_and_health_partnerships.pdf

Great Britain. Department of Health

Local Healthwatch : a strong voice for people : the policy explained.

London : DH, 2012

Web publication

This briefing describes the key policy ambitions for Healthwatch. It is aimed at all those with an interest in local Healthwatch organisations across the NHS and social care, including local authorities, local involvement networks, emerging health and wellbeing boards and the voluntary and community sectors.

<http://webarchive.nationalarchives.gov.uk/20130805112926/http://healthandcare.dh.gov.uk/files/2012/03/Local-Healthwatch-policy.pdf>

Associated documentation <http://healthandcare.dh.gov.uk/healthwatch-policy/>

ISBN: 9781907790324

Duffy, Simon

Centre for Welfare Reform

Peer power : an evaluation of the Personalisation Forum Group : a user-led organisation (ULO) for people in Doncaster.

Sheffield : Centre for Welfare Reform, 2012

Web publication

The Personalisation Forum Group (PFG) is a good example of a dynamic user-led organisation (ULO) that initially came together out of frustration with the current mental health system; but which has now worked together to bring about positive change in its local community. This report explores how it works with its statutory partners - Doncaster Metropolitan Borough Council (DMBC) and Rotherham, Doncaster and South Humber NHS Foundation Trust (RDASH).

<http://www.centreforwelfarereform.org/uploads/attachment/337/peer-power.pdf>

Related documentation:

http://www.centreforwelfarereform.org/library/type/pdfs/peer-power.html?utm_source=The+Centre+for+Welfare+Reform+Ltd+List&utm_campaign=ce1e621017-Regular+Newsletter+2012+06+126+11+2012&utm_medium=email

Frontline and InHealth Associates

An economic case for involvement.

London : Frontline, 2012

Web publication

This work, commissioned by the Department of Health, looks at the economic case for public and patient engagement as well as developing a decision support tool. Fourteen detailed case studies were carried out to identify how meaningful and effective involvement in commissioning can drive economic, quality and user experience benefits for the NHS and partner organisations – as well as the populations they serve.

http://www.networks.nhs.uk/nhs-networks/commissioning-zone/development/working-with-the-public/an-economic-case-for-patient-and-public-involvement-in-commissioning/An%20economic%20case%20for%20involvement%20v4.pdf/at_download/file

Lawton, Rebecca and Armitage, Gerry

The Health Foundation

The role of the patient in clinical safety

Thought paper ; (May 2012)

London : The Health Foundation, 2012

Web publication

In this thought paper, Dr Rebecca Lawton and Dr Gerry Armitage look at ways to involve patients in clinical safety and the readiness of patients and health professionals to adopt new roles. They discuss the importance of involving patients in the development of patient engagement and involvement strategies.

<http://www.health.org.uk/sites/default/files/TheRoleOfThePatientInClinicalSafety.pdf>

Coulter, Angela

The King's Fund

Leadership for patient engagement.

London : The King's Fund, 2012

Web publication

This paper was commissioned by The King's Fund to inform its review of leadership in the NHS.

Patient and public engagement has been on the NHS agenda for many years, but the impact has been disappointing. There have been a great many public consultations, surveys, and one-off initiatives, but the service is still not sufficiently patient-centred. In particular there has been a lack of focus on engaging patients in their own clinical care, despite strong evidence that this could make a real difference to health outcomes. This paper argues that a more strategic approach is required to create the necessary shift in beliefs, attitudes and behaviours.

<http://www.kingsfund.org.uk/sites/files/kf/leadership-patient-engagement-angela-coulter-leadership-review2012-paper.pdf>

ISBN: 9780957253308

Loeffler, Elke, et al.

Governance International and Local Government Information Unit

Making health and social care personal and local : moving from mass-production to co-production.

Birmingham : Governance International, 2012

Web publication

This publication brings together contributors from councils, health and social care providers, the voluntary sector and universities. Over 24 chapters the contributors look at the reality of health and social care co-production and the important difference it is making to people's lives and service delivery.

http://www.govint.org/fileadmin/user_upload/publications/2012_Pamphlet/Co-production_in_health_and_social_care.pdf

Local Government Association

Building successful Healthwatch organisations : 15 case studies.

London : LGA, 2012

Web publication

This report seeks to assist local authority commissioners and their supporting stakeholders, to help them plan and implement robust and fit-for-purpose Healthwatch bodies by April 2013. It is based on informed observations from emerging practice in 15 local Healthwatch case study areas across England.

http://www.local.gov.uk/c/document_library/get_file?uuid=876d0260-30e5-4cd9-9138-c868aa4b8baf&groupId=10180

National Voices

Not the Francis Report.

London : National Voices, 2012

Web publication

This report calls for greater urgency in improving patient safety and care quality. It warns that delays to the Francis Report could also create delays on improvements in care quality in the NHS and the report makes a number of recommendations for improving patient safety and the quality of patient care. These recommendations include greater patient and public involvement; the reorganisation of hospital services; and a drive towards integrated primary care.

http://www.nationalvoices.org.uk/sites/www.nationalvoices.org.uk/files/not_the_francis_report_final.pdf

Varah, Stephanie

NHS Networks

Practices and patient engagement.

Smart Guides to Engagement

[London] : NHS Networks, [2012]

This guide helps clinical commissioning groups (CCGs) engage in sustainable and useful ways with patient participation groups (PPGs) in a single general practice or linked together in networks across bigger geographical areas. These could be across CCG localities or the entire CCG.

http://www.networks.nhs.uk/nhs-networks/smart-guides/documents/Working%20with%20Patient%20Participation%20Groups.pdf/at_download/file

Smart Guides <http://www.networks.nhs.uk/nhs-networks/smart-guides>

Vincent, Robin, et al.

Panos London *and* Naz Project London

Beyond consultation : a guide for health commissioners : how staff and service users can work together to improve health services.

London : Panos London, Naz Project London, 2012

Web publication

This guide draws on lessons and practices from the Beyond Consultation project. They are included to illustrate how an effective engagement process can be put into practice. It details a series of steps designed to encourage genuine participation and engagement between staff and service users. For each step there are questions to guide decisions, useful practical methods and tools, expected outcomes and potential challenges.

<http://panos.org.uk/wp-content/files/2012/03/Beyond-Consultation-a-guide-for-health-commissioners.pdf>

JOURNAL ARTICLES

Waters, Adele

HSJ Patient Leaders.

Health Service Journal 2015; 125 (6454): 1-12 (22 July 2015 Suppl.)

The inaugural HSJ Patient Leaders recognises 50 outstanding individuals whose personal experiences have led them to instigate change and as a result are shaping healthcare. [Introduction]

Magtoto, Murphy, et al.

How a patient perspective improved IV therapy.

Nursing Times 2015; 111 (20): 16-17 (13 May 2015)

Cystic fibrosis (CF) treatment is demanding and includes courses of intravenous antibiotics (IVAB), for which many patients are admitted to hospital. Our 35-bed adult respiratory ward delivers antibiotic doses up to four times a day but time pressures meant most patients did not receive their antibiotics on time. Many adults with CF are expert patients and plan their care with the healthcare team so a patient-nurse partnership was set up to resolve this issue. This article outlines a radical service change, based on a patient's comments, that was piloted and received positive feedback. [Abstract]

Corrigan, Paul

Health services must be coordinated.

Health Service Journal 2015; 125 (6443): 18 (24 April 2015)

The authors emphasise the importance of service user involvement for the effective development and operation of coordinated care. [KJ]

Dalton, Jane, et al.

Service user engagement and health service reconfiguration : a rapid evidence synthesis.

Health Services and Delivery Research 2015; 3 (17): (April 2015)

BACKGROUND: UK NHS organisations are required to consult patients and the public about proposals for major changes to services. The evidence base for current UK guidance is unclear. OBJECTIVES: To assess what is known about effective patient and public engagement in reconfiguration processes and to identify implications for further research. DESIGN: Rapid evidence synthesis. SETTING: Health services affected by reconfiguration proposals in the UK (particularly the English) NHS and similar health systems. PARTICIPANTS: Members of the public and their representatives, patients and patient groups. INTERVENTIONS: Any intervention to encourage patients and the public and their representatives to be involved in discussions about proposals for major service change. MAIN OUTCOME MEASURES: Any measure of 'successful' engagement as reported by health service decision-makers, patients and public representatives. We were also interested in the outcome of controversial reconfiguration proposals. DATA SOURCES: We carried out separate searches for systematic reviews, primary research studies and grey literature. Database searches were limited to material published in English from 2000 to March 2014. REVIEW METHODS: Final decisions on study inclusion were made by two reviewers independently. We used EPPI-Reviewer 4 (Evidence for Policy and Practice Information and Co-ordinating Centre, University of London, London, UK) to record decisions and for data extraction and quality assessment. We carried out a narrative synthesis using multiple frameworks (including pre-specified research questions and current guidance). In synthesising the case studies, we selected a number of 'exemplars' based on quality of reporting and some evaluation of the process of engagement. RESULTS: Eight systematic reviews, seven empirical research studies and 24 case studies (six exemplars) were included. Methods of engagement varied in nature and intensity, and generally involved a mixed methods approach. There was no evidence on the isolated impact of any particular engagement method or collection of methods. In general, engagement was most likely to be successful when the process started at an early stage, offered opportunities for genuine interaction and was led and supported by clinicians involved in delivering the relevant services. The impact of engagement was variably measured and demonstrated. Impact was more frequently defined in terms of process measures than success or failure of reconfiguration. Little was reported on the potential negative impact of service user engagement. CONCLUSIONS: Patients and the public could be engaged through a wide variety of methods. In selecting which methods to employ locally, decision-makers should take into account the nature of the local population and of the proposed service changes. Problems often arose because decision-makers paid insufficient attention to issues considered important by the public. NHS England guidance could be a helpful practical framework for future engagement activity. FUTURE WORK: Clearly reported evaluations of interventions are needed including those that test the sustainability of methods of engagement and their impact over time. The NHS England guidance on planning and delivering service change may provide a foundation for the design of future research. FUNDING: Commissioned by the National Institute for Health Research Health Service and Delivery Research (HSDR) programme from the University of York HSDR Evidence Synthesis Centre (project no. 13/05/11). [Abstract]

Goodrich, Joanna and Stanley, Eleanor

Be seen and heard in the care discussion.

Health Service Journal 2014; 124 (6391): 26-27 (21 March 2014)

Experience based co-design brings patients and staff together to work out how service provision needs to change and what the solutions should be. Joanna Goodrich and Eleanor Stanley explore the success of this innovative online tool. [Introduction]

Homa, Peter

Listen and learn under one roof.

Health Service Journal 2015; 125 (6438): 26-27 (13 March 2015)

After engaging 6,000 patients, carers and staff through 215 'events in tents', one trust [Nottingham University Hospitals Trust] has developed a richer game plan on how to improve. Chief executive Peter Homa explains. [Introduction]

Smiddy, Jane, et al.

Developing patient reference groups within general practice : a mixed-methods study.

British Journal of General Practice 2015; 65 (632): 128-129 (March 2015)

BACKGROUND: Clinical commissioning groups (CCGs) are required to demonstrate meaningful patient and public engagement and involvement (PPEI). Recent health service reforms have included financial incentives for general practices to develop patient reference groups (PRGs). AIM: To explore the impact of the patient participation direct enhanced service (DES) on development of PRGs, the influence of PRGs on decision making within general practice, and their interface with CCGs. DESIGN AND SETTING: A mixed-methods approach within three case study sites in England. METHOD: Three case study sites were tracked for 18 months as part of an evaluation of PPEI in commissioning. A sub-study focused on PRGs utilising documentary and web-based analysis; results were mapped against findings of the main study. RESULTS: Evidence highlighted variations in the establishment of PRGs, with the number of active PRGs via practice websites ranging from 27 per cent to 93 per cent. Such groups were given a number of descriptions such as patient reference groups, patient participation groups, and patient forums. Data analysis highlighted that the mode of operation varied between virtual and tangible groups and whether they were GP- or patient-led, such analysis enabled the construction of a typology of PRGs. Evidence reviewed suggested that groups functioned within parameters of the DES with activities limited to practice level. Data analysis highlighted a lack of strategic vision in relation to such groups, particularly their role within an overall patient and PPEI framework). CONCLUSION: Findings identified diversity in the operationalisation of PRGs. Their development does not appear linked to a strategic vision or overall PPEI framework. Although local pragmatic issues are important to patients, GPs must ensure that PRGs develop strategic direction if health reforms are to be addressed. [Abstract]

Trueland, Jennifer

Engage patient to humanise the NHS.

Health Service Journal 2015; 125 (6437): 22-23 (6 March 2015)

For retailers, customer feedback informs better service. So what is stopping the NHS tapping into patients' views? [Introduction]

Hustwayte, Rob

Convert public protest into local engagement.

Health Service Journal 2015; 125 (6430): 19-21 (16 January 2015)

When two Sussex hospitals [Conquest Hospital, Hastings and Eastbourne District General Hospital] were unable to deliver safe care levels, clinicians engaged with the local population to find the best solution. [Introduction]

Hudson, Bob

Public and patient engagement in commissioning in the English NHS.

Public Management Review 2015; 17 (1): 1-16 (January 2015)

Public and patient engagement (PPE) has a limited record of achievement in the English National Health Service (NHS), and this has been further complicated by the split between commissioning and providing remits. The passage of the NHS and Social Care Act 2012 has opened up new possibilities for enhancing PPE in the commissioning of health care. This article outlines the new context, describes a conceptual framework for locating different sorts of PPE activity, and provides some practical illustrations. It argues for greater conceptual clarity and clearer understandings on the purpose of PPE as prerequisites to change. [Abstract]

Renedo, Alicia, et al.

Patient and public involvement in healthcare quality improvement : how organisations can help patients and professionals to collaborate.

Public Management Review 2015; 17 (1): 17-34 (January 2015)

Citizens across the world are increasingly asked to get involved in healthcare improvement. Yet how this should work is often unclear. We know that different aspects of the culture of the organisation where patient and public involvement (PPI) takes place are crucial for success or failure of participatory action (eg commitment and attitudes to PPI of key staff, understandings about the role of patient participants) but exactly how this affects PPI is not well understood. We draw on examples from our four-year qualitative study examining the patient involvement activities of a UK healthcare improvement initiative (Collaborations for Leadership in Applied Health Research and Care (known as CLAHRC) for North West London). We conducted in-depth interviews with patient participants and observed their participation. In this presentation, we show how patients used specific elements of organisational culture where they participated to help in their work to improve healthcare. We look at what aspects of organisational culture facilitated PPI, and through what processes this happened. We discuss how to orientate organisational culture so it helps rather than hinders patient involvement. [Abstract]

Peckham, Stephen, et al.

Commissioning for long-term conditions : hearing the voice of and engaging users : qualitative multiple case study.

Health Services and Delivery Research 2014; 2 (44): (November 2014)

Action needs to be taken by organisations at both national and local levels. PPEI (patient and public engagement and involvement) is a circular process and, in itself, extremely fragile. This circular process can be 'virtuous' - successful engagement leads to improved involvement and outcomes. However, where involvement is tokenistic or ends, patients and the public become disengaged and less involved and can be described as a 'vicious circle'. In addition, we identified a number of key methodological issues and areas for further research that should be considered by research funders and researchers undertaking research in the area of PPEI, including a need for research on PPEI with young people. [Conclusion]

http://www.journalslibrary.nihr.ac.uk/_data/assets/pdf_file/0003/131385/FullReport-hsdr02440.pdf

Associated documentation: <http://www.journalslibrary.nihr.ac.uk/hsdr/volume-2/issue-44>

Omeni, Edward, et al.

Service user involvement: impact and participation : a survey of service user and staff perspectives.

BMC Health Services Research 2014; 14 (491): (25 October 2014)

BACKGROUND: Over the last 20 years governments around the world have promoted user involvement in an effort to improve the quality of health services. Despite the growing emphasis placed on user involvement in England, there is a paucity of recent studies looking at how service users and professionals perceive the outcomes of user involvement policies. This study aimed to examine the overall levels of participation in service user involvement in mental health services among professionals and service users and ascertain their views on the impact of involvement activity on various areas of service delivery. **METHODS:** A cross-sectional survey of service users and providers within community mental health services. The sampling was carried out across three mental health Trusts, two serving people living in inner-city areas and a third covering a mixed rural/urban population. A questionnaire with closed and open ended questions was used to gather the responses of service users and frontline professionals. As a mixed methods study, the analysis consisted of both quantitative and qualitative approaches. **RESULTS:** Three hundred and two service users responded to the survey with a response rate of 48 per cent. One hundred and forty three frontline mental health professionals, 26.8 per cent of those approached submitted questionnaires. Almost half of service users (N=138, 45.7 per cent) and healthcare professionals (N=143, 55.9 per cent) reported having been involved in some form of user involvement activity. Although there were some differences in the responses of service users and frontline professionals, both groups reported that service user involvement was having a positive impact. **CONCLUSIONS:** The findings show that, within the three mental health trusts examined in this study, service user involvement has become widespread and is perceived by both staff and service users to be a good policy. The study had some important limitations. The questionnaire used was based on existing literature, however it was not subjected to psychometric testing. In addition, response rates were low, particularly among professionals. Despite the limitations, the findings are encouraging, offering important of insight into views and experiences of service users and healthcare staff. Further studies are needed to assess and investigate the topic on a national level. [Abstract]

<http://www.biomedcentral.com/1472-6963/14/491>

Piper, Stewart

How to empower patients, and involve the public.

Nursing Standard 2014; 29 (4): 37-41 (September 2014)

Patient empowerment and patient and public involvement are a focus for NHS policy, with an emphasis on patient decision making and representation as core features of a patient-focused NHS. Patient empowerment and patient and public involvement imply a rebalancing of power in the nurse-patient relationship. In reality this is complicated by wider issues of power and control in a complex health service influenced by professional agendas, healthcare leadership, government targets and a developing business culture. Despite these ideological and organisational constraints, there are many ways in which nurses can support aspects of individual patient empowerment and patient and public involvement. [Abstract]

Pollard, Lorraine, et al.

The impact of Patient Participation Direct Enhanced Service on patient reference groups in primary care : a qualitative study.

Quality in Primary Care 2014; 22 (4): 189-199

BACKGROUND: NHS policy documents continue to make a wide-ranging commitment to patient involvement, The Patient Participation Direct Enhanced Service (PP-DES), launched in 2011, aimed to ensure patients are involved in decisions about the range and quality of services provided and commissioned by their practice through patient reference groups (PRGs). The aim of this exploratory study is to review the impact of the PP-DES (2011- 13) on a sample of PRGs and assess how far it has facilitated their involvement in decisions about the services of their general practices. METHODS: A qualitative methods design, using semi- structured interviews and focus groups, was employed to explore the experiences and views of GP practice staff (n = 24), PRG members (n = 80) at 12 GP practices, and other stakeholders (« = 4). RESULTS: Wide variation in the role and remit of the participating PRGs was found, which broadly ranged from activities to improve practice resources to supporting health promotion activities. The majority of PRG members were unfamiliar with the PP-DES scheme and its aims and purpose. Stakeholders and practice staff felt strongly that the main success of the PP-DES was that it had led to an increase in the number of PRGs being established in the locality. CONCLUSION: The PP-DES scheme has been a catalyst to establish PRGs. However, the picture was mixed in terms of the PRGs involvement in decisions about the services provided at their general practice as there was wide variation in the PRGs role and remit. The financial incentive alone, provided via the DES scheme, did not secure greater depth of PRG activity and power, however, as social factors were identified as playing an important role in PRGs' level of participation in decision making. Many PRGs have to become more firmly established before they are involved as partners in commissioning decisions at their practice. [Abstract]

Nies, Henk

Communities as co-producers in integrated care.

International Journal of Integrated Care 2014; 14 (April 2014)

Integrated care has become too much a professionals' concept, in research and theory development, as well as in practice, especially in high-income countries. The current debate on integrated care is dominated by norms and values of professionals, while most of the care is provided by non-professionals. The paradigms of integrated care for people with complex needs need to be reconsidered. It is argued that non-professional care and care by local communities need to be incorporated as a resource and a co-producer of care. It seems fair to assume that the community as such can take a more prominent role in organising and delivering health and long-term care. This implies redefining professional and non-professional responsibilities and boundaries. The boundary between public and private space is losing its significance, as is the distinction between formal and non-formal care. It also requires renegotiating and transforming organisational boundaries. This has consequences for legislation, funding and professional qualifications, as well as for management and governance. It challenges current professional identities as well as identities of service users, their informal carers and citizens. It may also require new types of funding, including non-monetary currencies, time-sharing and social impact bonds. The challenge is that big, that it needs to be addressed at its smallest scale: the citizen in his social network and local community, being co-producer of really integrated care. [Introduction]

<http://www.ijic.org/index.php/ijic/article/view/1589/2419>

Farmer, Jane and Nimegeer, Amy

Community participation to design rural primary healthcare services.

BMC Health Services Research 2014; 14 (130): (21 March 2014)

BACKGROUND: This paper explores how community participation can be used in designing rural primary healthcare services by describing a study of Scottish communities. Community participation is extolled in healthcare policy as useful in planning services and is understood as particularly relevant in rural settings, partly due to high social capital. Literature describes many community participation methods, but lacks discussion of outcomes relevant to health system reconfiguration. There is a spectrum of ideas in the literature on how to design services, from top-down standard models to contextual plans arising from population health planning that incorporates community participation. This paper addresses an evidence gap about the outcomes of using community participation in (re)designing rural community health services. **METHODS:** Community-based participatory action research was applied in four Scottish case study communities in 2008–10. Data were collected from four workshops held in each community (total 16) and attended by community members. Workshops were intended to produce hypothetical designs for future service provision. Themes, rankings and selections from workshops are presented. **RESULTS:** Community members identified consistent health priorities, including local practitioners, emergency triage, anticipatory care, wellbeing improvement and health volunteering. Communities designed different service models to address health priorities. One community did not design a service model and another replicated the current model despite initial enthusiasm for innovation. **CONCLUSIONS:** Communities differ in their receptiveness to engaging in innovative service design, but some will create new models that fit in a given budget. Design diversity indicates that context influences local healthcare planning, suggesting community participation impacts on design outcomes, but standard service models maybe useful as part of the evidence in community participation discussions. [Abstract]

<http://dx.doi.org/10.1186/1472-6963-14-130>

Phillips, Andy and Morgan, Gareth

Co-production within health and social care : the implications for Wales?

Quality in Ageing and Older Adults 2014; 15 (1): 10-20

PURPOSE: It is well recognised that individuals have much to contribute to the care that they receive, with attendant benefits on outcomes and reduction in cost. The recognition of individuals who access care services as interdependent citizens embedded in both formal and informal support networks is a shift that acknowledges their active role as partners in management of their own care and in service innovation and development. The purpose of this paper is therefore to explore and illustrate some of the domains of co-production. **DESIGN/METHODOLOGY/APPROACH:** In this paper, the authors review the literature, both peer-reviewed and professional, in order to provide a broad and contemporary commentary on this emergent approach. This literature is critically summarised and presented along with a narrative that discusses the context in Wales, where the authors are based. The approach to this paper is to bring together existing knowledge and also propose potential avenues for further research and practise development. **FINDINGS:** There is a diverse literature on this topic and the application of co-production appears potentially transformational within health and social care. Implementation of the principles of co-production has the potential to improve health and social care services in a range of settings. Real changes in outcomes and experience and reduction in societal cost can be achieved by making the people of Wales active partners in the design and delivery of their own health and social care. **ORIGINALITY/VALUE:** This review offers a readily accessible commentary on co-production, which may be of value to a wide range of professional groups and policy makers. This paper also reflects an original attempt to summarise knowledge and propose further areas for work. Most importantly, this paper offers a start point for co-production to become a reality for service provision with all the attendant benefits that will arise from this development. [Abstract]

Trujols, Joan, et al.

Patient-reported outcome measures : are they patient-generated, patient-centred or patient-valued?

Journal of Mental Health 2013; 22 (6): 555-562 (December 2013)

BACKGROUND: In the past two decades, there has been a growing interest in the development of a more patient-centred approach to assessing treatment outcomes. This interest has resulted in the increasing use of patient-reported outcome measures (PROMs) in both clinical trials and usual clinical practice. AIMS: To briefly discuss the paucity of efficacy and effectiveness studies in the field of mental health (exemplified by schizophrenia, depression and opioid dependence) that significantly incorporate the patient's perspective. The limited concordance between the perspectives of patients and clinicians in outcome assessment is also addressed. Finally, we propose a new PROM classification system based on the degree to which these instruments incorporate the patient's perspective. CONCLUSIONS: PROMs may differ little from traditional instruments unless they truly incorporate the patient's perspective and not just the perspectives of clinicians and researchers. Efforts to develop new PROMs that provide a more patient-centred outcome assessment should use qualitative and participatory methods to capture and incorporate patient perspectives and values. [Abstract]

Locock, Louise, et al.

Testing accelerated experience-based co-design : a qualitative study of using a national archive of patient experience narrative interviews to promote rapid patient-centred service improvement.

Health Service and Delivery Research 2014; 2 (4): (February 2014)

Accelerated experience-based co-design delivered an accelerated version of EBCD, generating a comparable set of improvement activities. The national film acted as an effective trigger to the co-design process. Based on the results of the evaluation, AEBCD offers a rigorous and effective patient-centred quality improvement approach. We aim to develop further trigger films from the archived material as resources permit, and to investigate different ways of conducting the analysis (e.g. involving patients in doing the analysis). [Conclusion]

http://www.journalslibrary.nihr.ac.uk/data/assets/pdf_file/0013/112090/FullReport-hsdr02040.pdf

Associated documentation:

<http://www.journalslibrary.nihr.ac.uk/hsdr/volume-2/issue-4>

Rose, Diana, et al.

How do managers and leaders in the National Health Service and social care respond to service user involvement in mental health services in both its traditional and emergent forms? : the ENSUE study.

Health Services and Delivery Research 2014; 2 (10) (April 2014)

BACKGROUND: This study set out to measure the extent and perceived impact of service user involvement (SUI) in mental health services and to explore different forms of SUI, both collective and individual. The focus was on service users' (SUs') interactions with managers and other key decision-makers in the UK NHS and social care. The theoretical frameworks used were organisational theory and new social movement theory. [Introduction]

http://www.journalslibrary.nihr.ac.uk/data/assets/pdf_file/0015/117006/FullReport-hsdr02100.pdf

Associated documentation:

http://www.journalslibrary.nihr.ac.uk/hsdr/volume-2/issue-10?src=0614_B21

Airoldi, Mara

Disinvestments in Practice : overcoming resistance to change through a sociotechnical approach with local stakeholders.

Journal of Health Politics, Policy and Law 2013; 38 (6): (December 2013)

For health care, economists have developed cost-effectiveness analysis (CEA) as a "rational" analytic tool to set priorities. Attempts to use CEA to decide how to cut expenditures, however, have been met with stakeholders' resistance. This article presents an illustrative case study of the application of an approach explicitly designed to engage stakeholders with conflicting objectives in confronting tightening budgets. The outcome of this process, which engaged a group of stakeholders including patients, caregivers, clinicians, and managers, was a strategy that reconfigured services to produce more health gain at reduced total cost. I argue that the key factors that led to overcoming resistance to change were (1) the collective character of the deliberations; (2) the analysis of the whole pathway; (3) the presence of patients; and (4) the development of a model based on CEA principles, which provided a credible rationale for difficult decisions. [Abstract]

Getting engaged is a commitment to change.

Health Service Journal 2014; 124 (6419): 4 (17 October 2014)

Listening to service users' needs and helping them co-produce solutions means professionals loosening their grip on the controls and sharing responsibility for change with the populations they serve [says Lord Victor Adebawale, chair of the London Health Commission's engagement group]. [Introduction] <http://www.hsj.co.uk/Journals/2014/10/13/m/i/f/London-Health-Commission-supplement-17.10.14.pdf>

Doughty, Mark and Gilbert, David

The missing link in engagement.

Health Service Journal 2013; 123 (6363): 26-27 (16 August 2013)

Patient leadership and the benefits of engaging with the public have been widely discussed in the NHS since the Francis report, but it missed an opportunity to increase their involvement, write Mark Doughty and David Gilbert. [Introduction]

Ocloo, Josephine, et al.

Empowerment or rhetoric? : investigating the role of NHS Foundation Trust governors in the governance of patient safety.

Health Policy 2013; 111 (3): 301-310 (August 2013)

OBJECTIVES: Involving patients and the public in patient safety is seen as central to health reform internationally. In England, NHS Foundation Trusts are seen as one way to achieve inclusive governance by involving local communities. We analysed these arrangements by studying lay governor involvement in the formal governance structures to improve patient safety. METHODS: Interviews with key informants, observations of meetings and documentary analysis were conducted at a case study site. A national survey was conducted with all acute Foundation Trusts (n=90), with a response rate of 40% (n=36). Follow up telephone interviews were conducted with seven of these. RESULTS: The case-study revealed a complex governance context for patient safety involving board, safety and various sub-committees. Governors were mainly not involved in these formal mechanisms, with participation being seen to pose a conflict of interest with the governors' role. Findings from the survey showed some involvement of governors in the governance of patient safety. CONCLUSIONS: This study revealed a lack of inclusivity by Foundation Trusts of lay governors in patient safety governance. It suggests action is needed to empower governors to undertake their statutory duties more effectively and particularly through clarification of their role and the provision of targeted training and support to facilitate their involvement in the governance of patient safety. [Abstract]

Thomas, Kellie, et al.

Engaging patients, users and carers in integrated care.

London Journal of Primary Care 2013; 5 38-40

Engaging patients, users and carers is an important enabler of integrated care. We describe how the Inner North West London Integrated Care Pilot set up a Patients, Users and Carers Committee, found volunteers to join it, and helped to prepare them for their role. Representatives from the group were included in the membership of the Pilot's management board and committees and took part in several engagement and educational events. Some obstacles and challenges were encountered, including communicating with a large number of patient participation groups across the area, managing the high expectations of the group about how quickly reforms could be achieved, and ensuring that members of other committees understood the role of the representatives. Benefits included easy access to the perspectives of patients, users and carers when developing the strategy, policies and processes of the Pilot. Representatives proved to be eloquent advocates, and played a part in the success of the Pilot in winning some prestigious awards. [Abstract]

<http://www.radcliffehealth.com/ljpc/article/engaging-patients-users-and-carers-integrated-care>

Tritter, Jonathan Q. and Koivusalo, Meri

Undermining patient and public engagement and limiting its impact : the consequences of the Health and Social Care Act 2012 on collective patient and public involvement.

Health Expectations 2013; 16 (2): 115-118 (June 2013)

Patient and public involvement has been at the heart of UK health policy for more than two decades. This commitment to putting patients at the heart of the British National Health Service (NHS) has become a central principle helping to ensure equity, patient safety and effectiveness in the health system. The recent Health and Social Care Act 2012 is the most significant reform of the NHS since its foundation in 1948. More radically, this legislation undermines the principle of patient and public involvement, public accountability and returns the power for prioritisation of health services to an unaccountable medical elite. This legislation marks a sea-change in the approach to patient and public involvement in the UK and signals a shift in the commitment of the UK government to patient-centred care. [Abstract]

Dent, Emma

Piece of my mind.

Health Service Journal 2013; 123 (6354): 2-5 (7 June 2013 Suppl.)

'Value based' commissioning aims to put users' views at the heart of reshaping services. [Introduction]
http://www.hsj.co.uk/Journals/2013/06/06/f/s/x/HSJ_COMMISSIONINGSUPP_130607.pdf

Clarke, Robin and Rozansky, Deborah

The battle for hearts and minds.

Health Service Journal 2013; 123 (6352): 24-25 (24 May 2013)

The public is wary of the charges facing the NHS but local citizens can be won over if they are encouraged to contribute towards shaping health services early on, say Robin Clarke and Deborah Rozansky. [Introduction]

Fisher, Jonathan

Growing public engagement.

Health Service Journal 2013; 123 (6350): 22-23 (10 May 2013)

CCGs need to engage the public commissioning and not get bogged down with models and processes, says Jonathan Fisher. [Introduction]

Gerada, Clare

The community commitment.

Health Service Journal 2013; 123 (6349): 19 (3 May 2013)

If CCGs are to be a success, commissioners must work with communities, says Clare Gerada [chair of the Royal College of General Practitioners]. [Introduction]

Gilbert, David and Doughty, Mark

Taking the revolution one hurdle at a time.

Health Service Journal 2013; 123 (6340): 29-31 (21 February 2013)

In the third article in their series, David Gilbert and Mark Doughty take an in-depth look at the highs and lows experienced by patient leaders. [Introduction]

Ocloo, Josephine E. AND Fulop, Naomi

Developing a critical approach to patient and public involvement in patient safety in the NHS : learning lessons from other parts of the public sector?

Health Expectations 2012; 15 (4): 424-432 (December 2012)

There has been considerable momentum within the NHS over the last ten years to develop greater patient and public involvement (PPI). This commitment has been reflected in numerous policy initiatives. In patient safety, the drive to increase involvement has increasingly been seen as an important way of building a safety culture. Evidence suggests, however, that progress has been slow and even more variable than in health care generally. Given this context, the paper analyses some of the key underlying drivers for involvement in the wider context of health and social care and makes some suggestions on what lessons can be learned for developing the PPI agenda in patient safety. To develop PPI further, it is argued that a greater understanding is needed of the contested nature of involvement in patient safety and how this has similarities to the emergence of user involvement in other parts of the public services. This understanding has led to the development of a range of critical theories to guide involvement that also make more explicit the underlying factors that support and hinder involvement processes, often related to power inequities and control. Achieving greater PPI in patient safety is therefore seen to require a more critical framework for understanding processes of involvement that can also help guide and evaluate involvement practices. [Abstract]

Doughty, Mark and Gilbert, David

When patients become leaders.

Health Service Journal 2012; 122 (6320): 28-29 (13 September 2012)

In the second article in their series, Mark Doughty and David Gilbert [co-directors of the Centre for Patient Leadership] discuss the lessons about the self that can give patients the strength to lead others. [Introduction]

Gilbert, David and Doughty, Mark

Why patient leaders are the new kids on the block.

Health Service Journal 2012; 122 (6312): 26-27 (5 July 2012)

In the first of a series of articles, David Gilbert and Mark Doughty look at the roles patient leaders can play and the challenges they face. [Introduction]

Watson, Verity, et al.

Involving the public in priority setting : a case study using discrete choice experiments.

Journal of Public Health 2012; 34 (2): 253-260 (June 2012)

BACKGROUND: Health-care organizations need to prioritize their resource use and should incorporate the public's preferences into their priority setting process. METHODS: We apply a discrete choice experiment (DCE) to obtain weights, from the public, for use in a priority setting exercise. Ten attributes were chosen: location of care, public consultation, use of technology, service availability, patient involvement, management of care, evidence of effectiveness, health gain, risk avoidance and priority area. From the DCE responses, weighted benefit scores were calculated and used to rank development bids from across a health-care organization. RESULTS: Sixty-eight members of the public completed the DCE. All attributes except risk avoidance were significant. The most important attribute levels were a large health gain to many people: care being provided in teams, using latest or cutting-edge technology and 24 h service availability. Local priorities were valued higher than national priorities. Ninety-five bids were ranked in order of overall score. The ranked list of development bids provided a useful tool to inform prioritization decisions. CONCLUSIONS: DCEs can offer a theoretically valid and practical means of incorporating the views of the public in an accessible, transparent and streamlined decision-making process when health-care organizations are prioritizing their resources. [Abstract]

Allen, Pauline, et al.

Organizational form as a mechanism to involve staff, public and users in public services : a study of the governance of NHS foundation trusts.

Social Policy and Administration 2012; 46 (3): 239-257 (June 2012)

In addition to introducing markets and market-like structures into public services, New Labour wished to promote the involvement of users and the public in decision-making in other ways than as individual consumers. One way was to involve the public in the governance of organizations. This could be done by removing public services from state control, and transferring them to mutual ownership; or by increasing public involvement in the governance of public bodies. NHS foundation trusts (FTs) were presented as mutuals. Our study shows FTs are not mutuals, as they continue to be owned by the state. Moreover, staff of FTs were generally not engaging with the new governance structures. In general, there was mixed experience of the new structures enabling governors to increase accountability of the hospitals to the public. On the other hand, having a membership did enhance the legitimacy of FTs, as opposed to other NHS organizations. The findings of the study are of current interest as the coalition government is continuing with the policy of FTs, and also encouraging mutuals and other forms of public involvement. [Abstract]

Redding, Don

Giving some TLC to LTCs.

Health Service Journal 2012; 122 (6306): 27 (17 May 2012)

Don Redding of National Voices identifies three types of people who can enhance the commissioning of services for people with long term conditions. [Introduction]

Sanchez-Bahillo, Angel, et al.

Involving service users in the recruitment of mental health staff : the Service User Informed Tool for Staff Selection (SUITSS).

Psychiatrist 2012; 36 (4): 133-136 (April 2012)

AIMS AND METHOD: Service user involvement in the development of services is a fundamental aim of the National Health Service (NHS). However, a structured and quantifiable approach to their involvement in the recruitment of NHS staff is still lacking. In this study, we used service-user focus groups within a therapeutic community for people with personality disorder in order to develop the Service User Informed Tool for Staff Selection (SUITSS). RESULTS: We enabled service users to develop SUITSS as a Likert scale with which to define relevant staff characteristics and rate applicants according to them, informing the staff-selection process. The tool has a semi-quantitative format that allows to test whether applicants with higher ratings are actually appointed by selection panels or not. CLINICAL IMPLICATIONS: This new tool provides an approach to enhancing service user contributions to staff recruitment. It may be adapted and refined for use in a range of services, with local input from service users, following the approach described here. [Abstract]

Wright, John, et al.

The new governance arrangements for NHS foundation trust hospitals : reframing governors as meta-regulators.

Public Administration 2012; 90 (2): 351-369

New governance arrangements for NHS Foundation Trusts (FTs) aimed to replace centralized state ownership of acute English hospitals with a new form of social ownership. Under this, trusts would exist as independent public interest organizations on the model of mutuals and co-operative societies. Assessing the impact of the new arrangements on the management structure of four acute hospitals, we demonstrate that FTs have failed to deliver social ownership and local accountability on this model. We suggest that policy-makers should re-frame the governance apparatus associated with mutualism and social ownership in terms of the concept of meta-regulation. By re-framing governors as meta-regulators, regulatory institutions would acquire new powers to steer FTs towards sustainable forms of compliance via non-coercive, non-intrusive means. [Introduction]

McCabe, Louise

Supporting user participation in local policy development : The Fife Dementia Strategy.

Social Policy and Society 2012; 11 (2): 157-169 (April 2012)

This article reviews the consultation process during the development of a local dementia strategy. The processes of involvement by the range of stakeholders involved and how their different views shaped the strategy are considered. Particular attention is paid to the involvement of people with dementia as they are the recipients of the services to be shaped by the strategy and also form the group most difficult to reach. This article demonstrates the value of including a wide range of stakeholders in the development of local policy and the importance of involving people with dementia in policy development. [Abstract]

Meudell, Alan

User involvement in Wales.

Open Mind 2012; 171 15 (March 2012)

True 'service user involvement' can be achieved not through consultation only but through integration of user voices in policy and practice decisions. [Introduction]

WEB RESOURCES

Care Quality Commission - Share your experience

<http://www.cqc.org.uk/public/sharing-your-experience>

Centre for Health and the Public Interest

<http://chpi.org.uk/>

Centre for Public Scrutiny - Health and Social Care Reform Programme

<http://cfps.org.uk/scrutiny-and-the-health-reforms>

Healthwatch England

<http://www.healthwatch.co.uk/>

Involve

<http://www.invo.org.uk/>

The King's Fund

- Patient experience
<http://www.kingsfund.org.uk/topics/patient-experience>

National Association for Patient Participation (NAPP)

<http://www.napp.org.uk/>

National Involvement Partnership

<http://www.nsun.org.uk/about-us/our-work/national-involvement-partnership/>

National Voices

<http://www.nationalvoices.org.uk>

NESTA – Health Lab

<http://www.nesta.org.uk/health-lab>

NHS Choices

- Get involved in the NHS
<http://www.nhs.uk/NHSEngland/thenhs/about/Pages/getinvolved.aspx>

NHS England

- Patient involvement
<http://www.england.nhs.uk/ourwork/patients/>

Picker Institute Europe

<http://www.pickereurope.org/>