NIP List of Involvement Resources

Introduction

In this list, we have tried to include as many resources that we could find that address in various ways '*how to do*' or '*how to evaluate*' involvement, including a range of guides, toolkits, questionnaires, measures and frameworks. The resources are referenced with keywords and are loosely categorised in the same groups used in the NIP Standards for Involvement:

> A: Individual care
> B: Community involvement
> C: Operational (service delivery, projects, research, education and training)
> D: Strategic
> E: Monitoring and evaluation

All of the references for these resources are included in the NIP References document, and the items themselves will be kept on the NSUN website when we have designed a place for them. This is not a comprehensive list of involvement resources; we are keen to include any that you can recommend and will continue to update this list on a regular basis.

A: Involvement in Individual Care

1. **Direct Power**: A resource pack for people who want to develop their own care plans and support networks. By Alan Leader (1995). Joint publication by the Community Support Network, Brixton Community Sanctuary and Pavilion Publishing (Brighton) Ltd and Mind Publications. This is no longer available, but is interesting because it was developed by service users for service users as an empowerment tool. Sections covered include:
   - Building your own personal profile;
   - Experiences of services you are in contact with, and a
   - Self-assessment of needs Checklist.

   KEYWORDS: INDIVIDUAL; USER-LED; TOOLKIT

2. **Carers' and Users' Expectations of Services (CUES).** CUES was developed by a partnership of the Royal College of Psychiatrists, Royal College of Nursing, University of East Anglia and Rethink Mental Illness. An account of its development is given in an article by Lelliott et al (2001) in the British Journal of Psychiatry. User CUES (CUES-U) was intended as a tool to help service users to plan their support and care, to keep track of things in their lives and it was also used in surveys. However it was never evaluated as an outcomes measure. CUES covers 16 areas of life including: where you live, money and help with finances, family and friends, social life, mental health services, physical health services, choice and control and information. There is also a **carers' version** of CUES

developed in consultation with carers and another article in Journal of Mental Health refers to it (Lelliott et al, 2003). Carer CUES (CUES-C) is a self-rated 13 item questionnaire covering domains identified by carers. The User CUES document is available at http://mob.mhcc.org.au/media/3372/indiv-supports-consumer-carer-expectations-of-services-2012-12-14.pdf ; the Carers' version remains unfound.

KEYWORDS: INDIVIDUAL; MEASURE; CARERS; OUTCOMES

3. **Carer Wellbeing and Support Questionnaire (CWS)** This is a measure to evaluate outcomes in carers of people with mental health problems. It was developed in part from the above Carers version of the CUES. The authors describe deconstructing the existing questionnaire (CUES-C) to produce a long version measure. This was tried out with carers to reduce the number of items and they undertook a preliminary evaluation and a field test of the psychometric properties of the remaining items. They report that the CWS well-being scale shows moderate acceptability and good reliability and validity. Quirk A., Smith S., Hamilton S., Lamping D., Lelliott P., Stahl D., Pinfold V., and Andiappan M. (2012) "Development of the carer well-being and support (CWS) questionnaire", Mental Health Review Journal, Vol. 17 Iss: 3, pp.128 – 138. Full report to the Department of Health is here: www.rcpsych.ac.uk/pdf/CWS%20final%20report%20-%20SDO%20website%20version.pdf

KEYWORDS: CARERS; MEASURE; OUTCOMES

4. **My View: Putting my views at the heart of my mental health services and support.** NHS Quality Improvement Scotland with Vox Scotland (ULO) c. 2008. The My View needs assessment tool was based on the Avon Mental Health Measure which was developed with service users in Avon in 1996 originally. The Avon measure was then used in the Scottish Schizophrenia Outcomes Study (see 4 below) and revised to become My View. My View has now been disseminated to the service in Scotland as of 2011. The tool is available with guidance notes for staff from www.healthcareimprovementscotland.org/our_work/mental_health/programme_resources/my_view.aspx

KEYWORDS: INDIVIDUAL; OUTCOMES; USER-LED

5. **Scottish Schizophrenia Outcomes Study. Hunter, R. Cameron, R. 2006** (funded by NHS Quality Improvement Scotland) – used the Avon Measure and led to the My View project (above). We also have an extensive reference list for the Scottish Schizophrenia Outcomes study, supplied by Vicky Rigley of the Scottish Government. Full report and executive summary at: www.healthcareimprovementscotland.org/our_work/mental_health/programme_resources/schizophrenia_outcomes_study.aspx

KEYWORDS: OUTCOMES; MEASURE; INDIVIDUAL

6. **Recovery: A carer's perspective. Karen Machin and Julie Repper, 2013.** Briefing paper from ImROC (Implementing Recovery through Organisational Change) in partnership with the Centre for Mental Health and the NHS Confederation. Examines what Recovery means for the families and friends of people with mental health conditions. It suggests ways in which these informal carers can support Recovery and looks at how mental health services can give the best possible help to do this. It also provides information about key resources, including the Triangle of Care and a Wellbeing Recovery Plan for families and friends.
www.nhsconfed.org/~/media/Confederation/Files/public%20access/ImROC_briefing_Carers_ImROC.pdf

   KEYWORDS: CARERS; RECOVERY

7. **The Triangle of Care: Carers Included. Carers Trust, 2013.** The essence of this guide is to clearly identify the six key elements (standards) required to achieve better collaboration and partnership with carers in the service user and carer's journey through mental health services. For each element they suggest good practice examples and resources that may be helpful. The six key standards state that:
   1) Carers and the essential role they play are identified at first contact or as soon as possible thereafter.
   2) Staff are 'carer aware' and trained in carer engagement strategies.
   3) Policy and practice protocols re: confidentiality and sharing information, are in place.
   4) Defined post(s) responsible for carers are in place.
   5) A carer introduction to the service and staff is available, with a relevant range of information across the care pathway.
   6) A range of carer support services is available
   http://professionals.carers.org/health/articles/triangle-of-care,6802,PR.html

8. **East London NHS Foundation Trust: Advance Directive for Mental Health Guidelines**. www.eastlondon.nhs.uk/About-Us/Freedom-of-Information/Trust-Policies-and-Procedure/User-Involvement-Policies/Advance-Directive---Guidelines.pdf. These are useful guidelines in that they outline the legal status of stated preferences and the responsibilities of staff.

   KEYWORDS: INDIVIDUAL; ADVANCE DIRECTIVE; GUIDELINES

9. **South Essex Partnership NHS Foundation Trust: Advance Directive.** Nicely laid out document with three parts: about me, about my treatment preferences and anything else I want people to know. Available from: www.essex.gov.uk/Health-Social-Care/carers/Documents/Advance_Decisions_-_SEPT.pdf

KEYWORDS: INDIVIDUAL; ADVANCE DIRECTIVE

10. **Guidelines for People wishing to make an Advance Directive for Mental Health. (Kent NHS Trust/Kent County Council/Medway Council)** This has two parts: the first is about an individual's wishes about psychiatric treatment, and the second covers their personal and home life, for example: children, pets and other dependants, security and anyone they want notified of what is happening. It is available on the Kent and Medway NHS and Social Care Foundation Trust website: www.kmpt.nhs.uk/Downloads/Understanding-Mental-Health/Advance_Directive_for_mental_health_June03.pdf

KEYWORDS: ADVANCE DIRECTIVE; INDIVIDUAL; GUIDELINES

11. **Priory Group – with Together & the Mental Health Foundation (David Crepaz-Keay and Anne Beales) 2011/2** They have developed questionnaires for different client groups of the Priory – to find out how much involvement people have in the care they receive. Simple and easy to complete, developed for people with learning disabilities, children and young people, forensic.

KEYWORKDS: INDIVIDUAL; EVALUATION;

12. **The Advocacy Charter: defining and promoting key advocacy principles. Action for Advocacy (www.actionforadvocacy.org.uk).** Developed as a set of core principles for advocacy, the Charter was designed: to inform advocacy practice and training ; to raise awareness of the value of Advocacy; as a tool for negotiating with funding and commissioning bodies; and as a quality assurance mechanism. It has been very successful in uniting advocacy providers around the ten core principles, which are as follows:
    - Clarity of purpose
    - Independence
    - Putting people first
    - Empowerment
    - Equal opportunity
    - Accountability
    - Accessibility
    - Supporting advocates
    - Confidentiality
    - Complaints

These ten principles were contracted to seven in order to form the basis of the Quality Performance Mark in advocacy. The charter is available at: www.aqvx59.dsl.pipex.com/Advocacy%20Charter2004.pdf

KEYWORDS: ADVOCACY; PRINCIPLES; CHARTER

13. **Talking Points**: **personal outcomes approach – Practical guide and Briefing** June 2012. Ailsa Cook and Emma Miller for the Joint Improvement Team, Scottish Government. Developed by researchers working with the JIT of the Scottish Government, in partnership with service users and unpaid carers, partners, providers, and other organisations. It is about moving away from a service-led to an outcomes based approach in services. It offers *4 Outcome levels*: Individual; Service; Organisational; National; and *3 Outcome types*: Maintenance (quality of life); Change (short term removal of barriers); Process (how services are delivered/how people feel treated).

    They use the Talking Mats approach – which is a means of engaging with people who have communication difficulties. Includes outcomes for carers: quality of life for cared for person; quality of life for carer; managing the caring role; process outcomes. Main report has an appendix of prompts for outcomes – e.g. for adults living in the community.
    www.eastrenfrewshire.gov.uk/CHttpHandler.ashx?id=6985&p=0

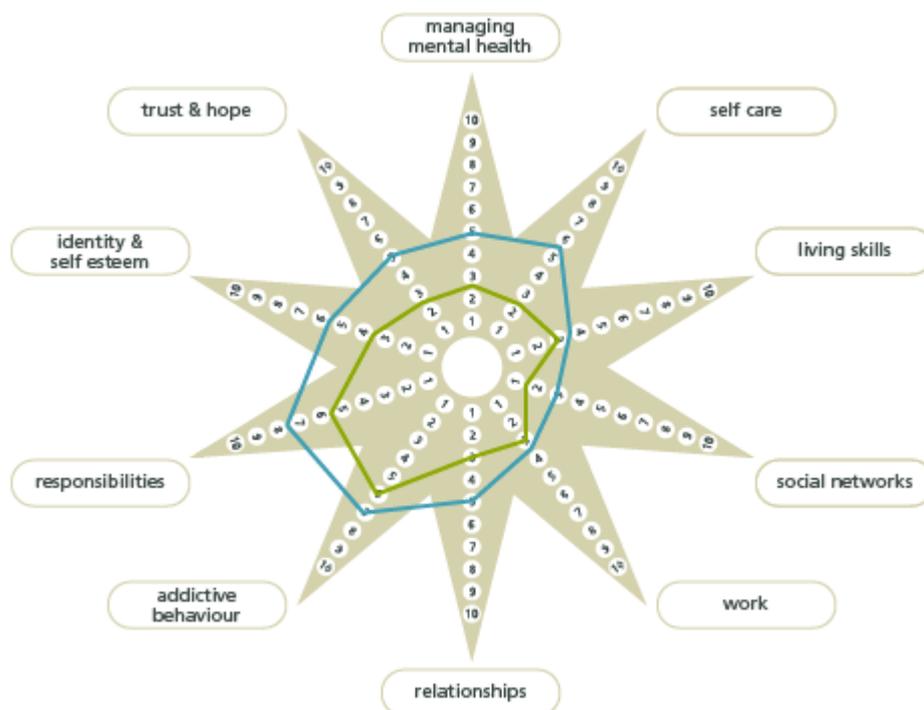   **KEYWORDS:** INDIVIDUAL; OUTCOMES; CARERS

14. **Involvement Triangle - the Torbay Toolkit Team, Supporting People (2006)**. Published by the Torbay Toolkit Team (Devon), it is based on the Outcomes Star which was developed by the London Housing Foundation and Triangle Consulting. The Triangle has self-assessment sheets and questionnaires for service users to fill in to assess their own involvement as well as support worker guides. Uses a scale of 1 to 10 on three dimensions or 'journeys':
    1. Involvement – make a positive contribution
    2. Meaningful use of time – enjoy and achieve
    3. Social networks and relationships – enjoy and achieve

    For more information contact the Torbay Supporting People team:
    www.torbay.gov.uk/supportingpeople

    KEYWORDS: INDIVIDUAL; OUTCOMES; TOOLKIT

15. **The Outcomes Star™ or Recovery Star – Triangle Consulting social enterprise.** The Outcomes Star is intended to measure and support progress for service users towards self-reliance or other goals. The Stars are designed to be completed collaboratively as an integral part of keyworking. There are sector wide tools for homelessness, mental health and young people. All versions consists of a number of scales based on an explicit model of change which creates coherence across the whole tool and a Star Chart (pictured below) onto which the service user and worker plot where the service user is on their journey. The attitudes and behaviour expected at each of the points on each scale are clearly defined, usually in detailed scale descriptions, summary ladders or a quiz format. [this information was taken from www.outcomesstar.org.uk/about-the-outcomes-star/].

KEYWORDS: INDIVIDUAL; OUTCOMES; TOOLKIT; RECOVERY

16. **ROLE Network** (Relating Outcomes to Lived Experience) Outcomes in Mental Health: Discussion Paper. November 2010. ROLE Network CIC, North West. http://rolegroup.files.wordpress.com/2011/02/role-outcomes2010.pdf They review a number of tools used to measure outcomes and do not favour any single tool. Rather, they conclude as follows:

"We suggest that an approach based on capabilities may encourage a holistic view and be less excluding. Acknowledging that choice is empowering, and control itself is a determinant of wellbeing, the report clearly states 'outcomes must be selected by service users and carers', and concludes: All we ask is that services always ask of each individual: **'What is most important to you and how might we achieve that with you?'** *(Findlater, 2008). As it says in Equity and Excellence: Liberating the NHS: 'Nothing about me without me' (Department of Health 2010)."*

KEYWORDS: INDIVIDUAL; OUTCOMES; USER-LED

17. **SUNSHINE Evaluation Tool. (Service User Need Spirituality, Health, Inclusion, Normalisation, Environment) NHS Bradford and Airedale, November 2010.** The SUNSHINE tool has its origins in the 'Commissioning Outcomes Framework' for Bradford's Black and Minority Ethnic (BME) Communities work undertaken in 2007/08. The tool allows for service users to identify their needs, providers to ensure identified needs are met and to demonstrate outcomes, whilst providing commissioners with information on where gaps in services lie. It was piloted by three organisations providing day services for people with mental health problems from BME communities. As a user led needs assessment tool

SUNSHINE allows service users to rate how well there are doing across a number of domains. The domains cover a range of aspects of social needs and healthcare. It allows service users to identify their changing needs over time, and plan how to make positive changes in their lives. Although similar to the Outcomes Star, it was felt by the team that the domains in the Outcomes Star did not fully correlate with those developed locally with BME communities.
Evaluation report available at: www.bradford.nhs.uk/wp-content/uploads/2010/07/SUNSHINE-evaluation-report.pdf or: www.better-health.org.uk/resources/research/evaluation-report-sunshine-pilot-bradford-february-september-2010

KEYWORDS: INDIVIDUAL; EVALUATION; DIVERSITY; OPERATIONAL

18. **Developing partners cic: Body mapping 'So What's Changed?'** 'developing partners cic' (www.developingpartners.org.uk) a community interest company in Stockton On Tees, developed an evaluation tool designed for people who have difficulty reading and writing, including people whose first language is not English. This tool was designed to make it easier for people whose first language was not English to evaluate the role of developing partners in their recovery journeys by using a drawing of the human body as well as using words (see figure below)

So What's Changed?
Body mapping
© Jacqui Lovell dp 2011
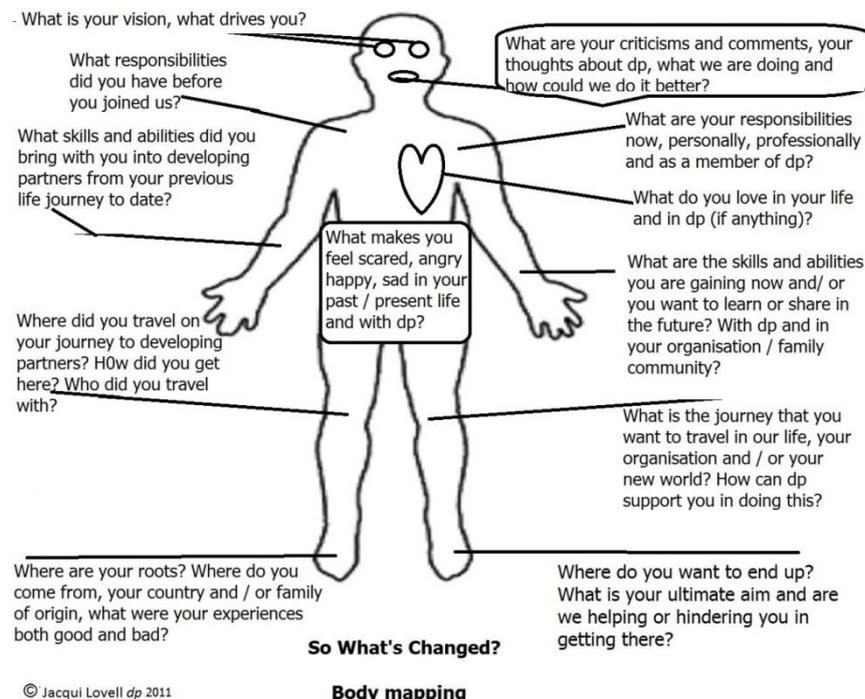
B: Community Involvement

19. **BIHR Mental Health Advocacy and Human Rights:** Your Guide. This guide is written in partnership with several mental health organisations, including Mind in Brighton and Hove, Wish and NSUN. It was designed to assist advocates working with service users with mental health problems. Much of the information will also be directly relevant to service users, in particular the sections 'How the Human Rights Act works' on page 7 and 'Key human rights relevant to mental health' on page 9.
www.bihr.org.uk/sites/default/files/BIHR_mentalHealth%20Guide_WEB.pdf

    KEYWORDS: ADVOCACY; RIGHTS; GUIDE

20. **EHRC: Equality and Human Rights Commission (2010) The United Nations Convention on the Rights of People with Disabilities: What does it mean for you?** London: EHRC. This guide was produced to introduce disabled people and disabled people's organisations to their rights, the role of the UNCRPD and how to make use of it to challenge injustice and improve services.
www.equalityhumanrights.com/sites/default/files/documents/publications/uncrpdguide.pdf

    KEYWORDS: RIGHTS; UNCRPD

21. **Seebohm, P. and Gilchrist, (2008) 'Connect and Include: an exploratory study of community development and mental health'.** National Social Inclusion Programme/Community Development Foundation. The authors describe 'community wellbeing' as 'a situation where communities are thriving, with many connections between individuals, groups, institutions and services, creating a sense of belonging'. They see wellbeing for the individual and the community as interdependent, and identified a number of activities and outcomes in relation to community development in a mental health context, including establishing trusting relationships, facilitating social and economic inclusion, increased learning, promoting equality and social justice.
www.cdf.org.uk/wp-content/uploads/2012/12/Connect_and_Include.pdf

    KEYWORDS: COMMUNITY; WELLBEING

22. **A glass half-full: how an asset approach can improve community health and well-being - Foot and Hopkins (2010) for the Improvement and Development Agency (IDeA) Healthy Communities Team.** This is based on Asset Based Community Development - on the principle of identifying and mobilising individual and community 'assets', rather than focusing on problems or deficits. This report offers practitioners and politicians, who want to apply the principles of community-driven development as a means to challenge health inequalities, a set of structured techniques for putting these asset-based principles and values into practice. www.bankofideas.com.au/Downloads/GlassHalfFull.pdf

See also the ABCD Institute (U.S. Northwestern University) for more downloadable resources and toolkit: www.abcdinstitute.org/publications/downloadable/

KEYWORDS: ASSETS; PRINCIPLES; COMMUNITY

23. **Building Resilient Communities: Making every contact count for public mental health (Mind, 2013)** Mind and the Mental Health Foundation published materials on building resilient communities on behalf of the Mental Health Strategic Partnership with funding from the Department of Health. They describe three key factors that affect resilience: activities that promote wellbeing; building social capital and developing psychological coping strategies. One of the materials they have produced is a practical guide for community groups and service providers, available on their website at: Mind & MHF building resilient communities materials: www.mind.org.uk/publicmentalhealth

KEYWORDS: PUBLIC MENTAL HEALTH; RESILIENCE; COMMUNITY; GUIDELINES

24. **WARM - The Wellbeing and Resilience Measure (Mguni and Bacon, 2010**) was developed by the Local Wellbeing Project of The Young Foundation. The idea of this programme was to explore how local government could improve the wellbeing of its citizens. The Wellbeing and Resilience Measure (WARM) is a framework to measure wellbeing and resilience at a local level and was designed to help local areas and the agencies that work in them understand their own capabilities and needs. http://youngfoundation.org/wp-content/uploads/2012/10/Taking-the-Temperature-of-Local-Communities.pdf

KEYWORDS: WELLBEING; MEASURE; LOCAL

25. **The Mental Wellbeing Impact Assessment toolkit** (published by the National Mental Health Development Unit (NMHDU) and updated 2011) uses a combination of methods, procedures and tools to assess the potential for a policy, service, programme or project to impact upon the mental well-being of a population. The MWIA theory and practice was developed in partnership with the National Collaborative on Mental Well-being Impact Assessment. The aims of the MWIA toolkit are to:
- Raise awareness and understanding of mental well-being;
- Enable a range of stakeholders to begin to identify the impact a particular policy, service, programme or project may be having on mental well-being;
- Encourage stakeholders to explore ways to maximise potential positive impacts and minimise potential negative ones;
- Enable stakeholders to explore and develop local indicators to monitor and evaluate progress on promoting mental well-being.

It focuses on population groups who may experience health inequalities and social injustice with a particular emphasis on those most at risk of poorer mental

well-being. It also makes the link with social determinants. The MWIA toolkit and reports are available on the HIA gateway:
www.apho.org.uk/default.aspx?RID=70494

KEYWORDS: WELLBEING; IMPACT; TOOLKIT; COMMUNITY

26. **Growing Social Capital: A social return on investment analysis of the impact of voluntary and community sector activities funded by grant aid. Wright and Shifferes, (2012) Kirklees Council with nef consulting.** This report is of a study with Kirklees Council to explore the extent to which fostering social capital activities contributes to positive improvements in well-being for individuals and communities, using the SROI model. Social Return on Investment (SROI) is a model and a measurement framework developed by the Community Development Foundation and nef (the new economics foundation) to help organisations to understand and manage the social, environmental, and economic value of their activities. It takes into account the full range of social benefits to all stakeholders, rather than simply focusing on revenue or cost savings for one stakeholder. SROI enables a ratio of benefits to costs to be calculated. For example, a ratio of 3:1 indicates that an investment of £1 delivers £3 of social value. It values things that matter to communities and attempts to put on value on such things as self-esteem and confidence. Report available at: www.thinklocalactpersonal.org.uk/_library/BCC/Growing_Social_Capital_SROI_-_March_2012.pdf

KEYWORDS: SROI; COMMUNITY; WELLBEING

C: Operational: involvement in services, activities, projects

General guidelines

27. **Making a Real Difference Good Practice Guidelines 2006**. developed by NIMHE South West (?with or by service users). Has a set of key principles with guidance points under each:
    - Be clear
    - Be inclusive
    - Treat people equally
    - Have a positive attitude
    - Ensure good communication and information
    - Have good physical accessibility
    - Adopt a good procedure
    - Ensure support is available
    - Have resources available
    - Create meaningful involvement
    - Consider all practical issues – before, during and after.

    NB All of the MARD (Making a Real Difference) products are available on the NSUN website: www.nsun.org.uk/get-involved/survivor_involvement/

    KEYWORDS: GOOD PRACTICE GUIDELINES; MARD; OPERATIONAL

28. **SCIE Practice Guide 17 and Summary: The Participation of adult service users, including older people, in developing social care. 2008.**
    Very useful report and 20 page summary. Proposes a whole systems approach to participation with organisations as a 4-piece jigsaw comprising: culture, structure, practice and review. Says, of purpose, that participation is more than simply being present – it should be about having an influence over decisions at many levels, from day-to-day decisions about, for example, what to eat up to collective decisions about how services are run or commissioned. Culture is about the ethos and values of the organisation, practice is about the ways of working, structure is about the planning, development and resourcing of participation. Review refers to the fact that organisations need to make a commitment to monitor and evaluate systems to evidence change through participation. It includes a checklist for evaluation and action points for reviewing participation.
    The summary: www.scie.org.uk/publications/guides/guide17/files/guide17-summary.pdf
    Main guide: www.scie.org.uk/publications/guides/guide17/files/guide17.pdf

    KEYWORDS: OPERATIONAL; PARTICIPATION; GOOD PRACTICE; CHECKLIST; EVALUATION; STRATEGIC

29. **Wallcraft J. and Bryant M. (2003) The Mental Health Service User Movement in England. Policy Paper 2, Centre for Mental Health.**

Based on the national survey of service user groups in England 'On Our Own Terms', this recommends the production of national good practice guidelines for user involvement based on the following 10 criteria:
1. Making user involvement the norm.
2. Providing a base of support and accountability.
3. Examining and dealing with power imbalances.
4. Professionals should reach out and visit service user groups more often rather than expecting service users to go to professionals' meetings.
5. Enabling service users/survivors to make their own decisions about involvement.
6. Valuing the skills of service users/survivors and helping them gain new skills and confidence.
7. Providing financial compensation for service user/survivor services.
8. Providing user involvement training for professionals.
9. Distinguishing between the needs of users and carers.
10. Ensuring the development of effective user involvement policies for NHS trusts and RDCs, together with programmes for acting on the outcomes of involvement.

www.centreformentalhealth.org.uk/pdfs/policy_paper2_service_user_movement.pdf

KEYWORDS: GOOD PRACTICE; USER-LED; RESEARCH; OPERATIONAL

30. **Together Good Practice Guide to Valuing, Respecting and Supporting Service User Activity.** Together for Mental Wellbeing Service User Involvement Directorate, 2006. This covers themes of Ownership; Independence; Valuing Involvement; Payment methods; Employing staff; Evaluation and accountability; Safety and support; Mediation. www.together-uk.org/wp-content/uploads/downloads/2011/09/togethergoodpracticeguide.pdf

KEYWORDS: GOOD PRACTICE GUIDELINES; OPERATIONAL;

31. **Briefing on 'Service User Involvement in the Delivery of Mental Health Services' - Together for Mental Wellbeing and NSUN (2014).** *** www.together-uk.org/wp-content/uploads/downloads/2014/06/Service-User-Involvement-briefing.pdf

KEYWORDS: OPERATIONAL; GUIDE; USER-LED

32. **Portsmouth User Involvement Charter;** this states that 'Those with experience of using services should be involved in improving the quality of services and participate in decisions about the way they are designed and managed. People should be able to contribute to these processes in a range of ways; with every aspect, including planning, purchasing, prioritising, monitoring, reviewing, and staff recruitment / training.
Involvement should be an on-going, developmental process, not a one-off project or exercise. It states that, before involving people, it is necessary to ask...

- Are the reasons for involving people clear?
- Is there commitment to the process?
- Is there adequate funding?
- Is there commitment to act upon service users involvement?
- Is there a service user involvement strategy?

The Charter is a two-way process and hopes to bring about a positive partnership for meaningful and valuable experiences. *'Successful involvement derives from a genuine and positive partnership, mutually respecting the contribution of all'.* Further information is at www.thinkingahead.org.uk/documents/PSUI%20Charter.pdf but the charter itself is not easily available.

KEYWORDS: CHARTER; OPERATIONAL; PARTNERSHIP

33. **Mind Engagement Toolkit** written and researched by Naomi Gay; this is being reviewed and updated (as of July 2014). This toolkit is for internal use only, although members of the Mind Engagement Team may be able to make it available to people on request. The toolkit uses four levels of 'engagement':
    - 1st stage consultation, questionnaires and e-campaigning
    - In depth consultation, participants can express views outside of fixed questions
    - Deciding and/or acting together, in partnership
    - Encouraging/providing a platform for initiatives led by people with personal experience

    This document is based on a RESPECT engagement cycle:
    Recruit participants – Expectations – Support – Plan – Evaluate – Change – Time to feedback. Good practice guidance is given under each of these headings. Enquiries to the Mind Engagement Team. Mind website: www.mind.or.uk

    KEYWORDS: TOOLKIT; LADDER; CYCLE; OPERATIONAL

34. **Waltham Forest Service User Involvement Charter 2004.** Jointly developed and signed up to by social services, PCT, local Trusts and the Service User Involvement Project. The charter states that meaningful service user involvement is not possible unless it spans the full range of service provision, including individual care planning. This is interesting as it includes reference to the importance of capacity-building and support to self help groups and to wider forums of service users as well as the direct involvement in services. The Principles in the charter are laid out with their aims alongside and include service user involvement in treatment and care, support to self-help groups, capacity building, support of wider forums, monitoring and evaluation, and contractual standards for involvement. [NO ONLINE SOURCE FOUND]

    KEYWORDS: CHARTER; PARTNERSHIP; OPERATIONAL; STRATEGIC

35. **Mental Wellbeing Impact Assessment toolkit**. Updated 2011. [SEE ALSO 24] This uses 'a combination of methods, procedures and tools to assess the potential for a policy, service, programme or project to impact upon the mental well-being of a population. MWIA makes evidence based recommendations to strengthen the positive and mitigate against the negative impacts, and encourages a process to develop indicators to measure impacts.'
MWIA theory and practice has been developed by a partnership in England. It is a huge document, and is highly rated by some people. MWIA toolkit and reports are available on the HIA gateway - www.apho.org.uk/default.aspx?RID=70494
   ▪ Also includes: Mental Well-being checklist – NMHDU

   KEYWORDS: WELLBEING; OPERATIONAL; IMPACT; TOOLKIT; COMMUNITY

Diverse groups and communities

36. **Beyond the Usual Suspects – Beresford, 2013 (Shaping Our Lives www.shapingourlives.org.uk)** Beyond the Usual Suspects usefully identifies both 'existing exclusions' (equality issues, where people live, communication issues and the nature of impairments) and external barriers to involvement. The barriers listed include: devaluing service users, welcoming some views more than others, tokenism, stigma, confidence and self-esteem, financial barriers, language and culture and inadequate information about involvement. Another issue of particular significance to marginalised groups is that of fear: fear that if you say something critical about a service, this will result in some kind of reprisal.

   This was originally published as a report; there are now a number of accompanying documents: research report, findings, practical guide and a number of useful resources available as pdfs. All available at:
   www.shapingourlives.org.uk/ourpubs.html

   KEYWORDS: BARRIERS; DIVERSITY; INCLUSION; OPERATIONAL

37. **Dancing to Our Own Tunes by Jayasree Kalathil; published by NSUN/Afiya Trust** (originally published 2008, it was reviewed in 2011 and reprinted in 2013). Includes guidelines and Charter for partnership working with BME service user/survivor led organisations which address issues such as: positive and enabling attitudes, empowerment and an acknowledgement of the discriminatory experiences that people from BME communities face in society, services and user involvement initiatives. The guidelines cover issues under the following headings: Values; Setting up partnerships; Management and Good practice. Available on the NSUN website:
   www.nsun.org.uk/assets/downloadableFiles/dtoots-report---for-website2.pdf

   KEYWORDS: DIVERSITY; GOOD PRACTICE; CHARTER; USER-LED

38. **'Doing it for themselves: participation and black and minority ethnic service users' by Nasa Begum. SCIE Participation Report 14 2006.** Very good. Explodes some myths about BME service users and involvement/participation. Available at: www.scie.org.uk/publications/reports/report14.pdf

    KEYWORDS: DIVERSITY; OPERATIONAL; USER-LED; BME

39. **Participation… Why Bother? The views of Black and Minority Ethnic mental health service users on participation in the NHS in Bradford – Heather Blakey, 2005.** Report of a community research project undertaken by the International Centre for Participation Studies, University of Bradford and Sharing Voices (Bradford). Report available from NSUN. Also an article by the same name in Mental Health Today: Mental Health Today, May 2006, pp.23-26.

    KEYWORDS: OPERATIONAL; DIVERSITY; RESEARCH; BME

40. **MARD (Making a Real Difference) Minimum Standards for Working with Diverse Groups and Communities (CSIP/NIMHE 2006**). Another in the MARD series of guidelines on involvement developed by NIMHE/CSIP in the mid 2000s. One of the strongest messages from the "Making A Real Difference" consultation that prompted the development of the guidelines, was the need for NIMHE to promote greater diversity and equality of service user and carer involvement. These standards are the result of the work to address that theme. There are 10 standards:
    1. Take a positive attitude to diversity, which celebrates different cultures and respects every person as an individual
    2. Address the structural barriers to involvement faced by different groups and communities, including the impact of discrimination
    3. Provide practical and personal support to enable the participation of service users and carers from a wider range of backgrounds
    4. Make information more accessible to the individuals, groups and communities with whom they are working
    5. Make events and activities inclusive of the individuals, groups and communities with whom they working
    6. Develop more flexible and creative ways of engaging different groups and communities
    7. Show its commitment as an organisation to mainstreaming equality and diversity of service user and carer involvement in its corporate policies, procedures and workforce
    8. Build upon existing networks, resources and positive practice
    9. Develop mutually supportive relationships with local communities and stakeholder groups
    10. Ensure its systems of service user and carer involvement support the needs of diverse groups and communities

    As with all of the MARD guidelines, this is available on the NSUN website: www.nsun.org.uk/get-involved/survivor_involvement/

KEYWORDS: OPERATIONAL; STANDARDS; DIVERSITY; MARD

41. **MARD Ways of Working with Diverse Groups and Communities (CSIP/NIMHE 2007)** One of the Making a Real Difference (MARD) series of guidelines on involvement produced under NIMHE/CSIP. This document takes a practical approach to presenting some different ways of approaching and working with diverse groups and communities. Available at: www.nsun.org.uk/get-involved/survivor_involvement/

    KEYWORDS: OPERATIONAL; DIVERSITY; GOOD PRACTICE

42. **CIH (Chartered Institute for Housing) Equality and Diversity Charter for Housing July 2012**. Nicely designed, good example of a charter. It is focused on outcomes. They say it can be used as a self-assessment framework. CIH offers a free open-access website to people who sign up to it; plus organisations are invited to upload short practice examples. They also join the equality and diversity network where signatories can share ideas, expertise and knowledge to drive improvements across the housing sector…

    KEYWORDS: DIVERSITY; CHARTER; HOUSING; OPERATIONAL

43. **'Ensuring Better Involvement of Black and Minority Ethnic Service Users and Carers in Mental health services'. Regional Toolkit: (Nottinghamshire Healthcare NHS Trust 2010**) – funded by the East Midlands Development Centre of NIMHE. This is not really a toolkit; it was developed as result of a 'rigorous and extensive' process of consultation with BME service users, carers, community development workers & service providers in Nottinghamshire. The report outlines three main barriers to the involvement of BME service users and carers and outlines ways of tackling each one. The barriers are: communication, accessibility, culture. www.better-health.org.uk/resources/toolkits/regional-toolkit-ensuring-better-involvement-black-and-minority-ethnic-service-us

    KEYWORDS: DIVERSITY; BARRIERS; TOOLKIT; BME; OPERATIONAL

44. **'We Care Too: A Good Practice Guide for People Working with Black Carers. The National Black Carers/Carers' Workers Network (2002).** This guide sets out standards for working well with black family carers across health and social care under three headings: assessment, respite and communication and information. Report available from NSUN.

    KEYWORDS: CARERS; DIVERSITY; GOOD PRACTICE; BME

45. **'Beyond We Care Too: Putting Black Carers in the Picture'. National Black Carers/Carers' Workers Network (2008)**. Based on extensive consultations and a review of existing evidence (including the 'We Care Too' document, above) in the

context of the development of a new national carers strategy, this document consolidates the experiences of black family carers and carer support services in relation to the needs of BME communities.
www.afiya-trust.org/images/files/afiya_beyond_we_care_too.pdf

KEYWORDS: CARERS; DIVERSITY; GOOD PRACTICE

Research/evaluation of services

46. **A Guide to User-Focused Monitoring: Setting up and running a project. by Nutan Kotecha and others, (2007) London: The Centre for Mental Health**. This is a guide to evaluating mental health services from a service user perspective. They present ten 'essential criteria' for UFM Projects to provide good principles for monitoring and/or evaluating services. These criteria include the following:
    1. Projects should be led and controlled by service users (e.g. more than half of any management structure/steering group should be service users)
    2. Clear focus on development & improvement of those services most frequently used by service users, esp. people from marginalised groups
    3. Active commitment to secure the participation of service users who have used the services under evaluation, including those whose voices are rarely heard.

    Available from the Centre for Mental Health:
    www.centreformentalhealth.org.uk/pdfs/user_focused_monitoring_guide_extract.pdf

KEYWORDS: RESEARCH; USER-LED; DIVERSITY; EVALUATION

47. **The Ethics of Survivor Research: guidelines for the ethical conduct of research carried out by mental health service users and survivors by Alison Faulkner, 2004; Policy Press**. JRF funded this piece of work; a consultation with service users/survivors about good practice in ethical service user/survivor research in mental health. This was produced by a survivor researcher in consultation with others and covers the following:
    * Underlying principles
    * Planning and design of research
    * Recruitment and involvement
    * Training, support and supervision
    * Involving participants
    * Analysis and feedback
    * Dissemination and implementation
    * Research ethics committees

Available from the Policy Press and from the Joseph Rowntree Foundation website: www.jrf.org.uk/publications/ethics-survivor-research-guidelines-ethical-conduct-research-carried-out-mental-health-

KEYWORDS: RESEARCH; GOOD PRACTICE; USER-LED; GUIDE

48. **Mental health researchers' toolkit for involving service users in the research process** (**June 2011**) - **produced by the Mental Health Research Network (MHRN) North London Hub Service User Representative Group**: David Armes, Jackie Barrett, David Hindle, Fenella Lemonsky and Jennifer Trite.. Includes a series of template documents including role descriptions, sample involvement agreement, application forms and evaluation forms for researchers and service users to fill in to assess their experience of involvement.

    KEYWORDS: OPERATIONAL; RESEARCH; TOOLKIT; USER-LED; TEMPLATES

49. **Good practice guidance for the recruitment and involvement of service user and carer researchers (2014).** Updated and revised version of earlier guidance produced by the Mental Health Research Network - this was produced just before the MHRN was dissolved. Available at: www.crn.nihr.ac.uk/wp-content/uploads/mentalhealth/UserCarerResearcherGuidelinesMay2014_FINAL.pdf

KEYWORDS: OPERATIONAL; RESEARCH; USER-LED;

Training and education

50. **Learning from Experience**: **Involving service users and carers in mental health training and education. A good practice guide by Jerry Tew, Colin Gell and Simon Foster, 2004 (updated 2011).** mhhe / NIMHE West Midlands / Trent NHS Workforce Development Confederation. Includes reference to Premila Trivedi's *Involvometer* and uses an adapted version of it plus other checklists for involvement. It uses a 'ladder of involvement' with 5 levels: Level 1 = No involvement; Level 2 = Limited involvement; Level 3 = Growing involvement; Level 4 = Collaboration; Level 5 = Partnership.
    Available at: http://mhhehub.ning.com/page/learning-from-experience

    KEYWORDS: OPERATIONAL; EVALUATION; CHECKLISTS; TRAINING/EDUCATION; LADDER;

51. **Involving Service Users and Carers in Education: The Development Worker Role. Guidelines for Higher Education Institutions by DUCIE (Developers of User and Carer Involvement in Education), 2009.** Published by DUCIE/mhhe (mental health in higher education).
    http://eprints.lancs.ac.uk/69396/1/ducie_guidelines.pdf

    KEYWORDS: OPERATIONAL; TRAINING/EDUCATION; GUIDE; CARERS;

Particular service/service groups

52. **Developing User Involvement**: *Working towards user-centred practice in voluntary organisations.* **Paul Robson, Nasa Begum and Michael Locke (2005) Joseph Rowntree Foundation.** Findings of an action research project funded by JRF which aimed to support the implementation of increased user involvement in governance and management of traditionally structured charities; to develop and demonstrate methods for the management of change that include users, staff and trustees; and to monitor and evaluate the impact of increased user involvement from user and organisational perspectives. It says, of the importance of the *presence* of service users in a variety of settings, that it enables organisations to change. Presence has potential impacts on four levels:
    - It gave opportunities to influence formal decision-making processes;
    - It demonstrated that users were interested in getting involved;
    - It gave opportunities to become part of networks of users and others;
    - It gave opportunities to learn about each other's experiences and priorities.

    However, presence without influence is also possible – and manifests tokenism. To guarantee responsive service development, service users need to have a high presence and a high level of influence.
    On Joseph Rowntree website: www.jrf.org.uk/sites/files/jrf/jr146-user-involvement-voluntary.pdf

    KEYWORDS: VOLUNTARY SECTOR; GOVERNANCE; STRATEGIC; OPERATIONAL

53. **Unlocking Service User Involvement Practice in Forensic Settings – NSUN/WISH, 2011.** Research into the provision of service user involvement in secure settings**.** Available on the NSUN website:
    www.nsun.org.uk/assets/downloadableFiles/unlocking-forensic-ui--final-version2.pdf

    KEYWORDS: OPERATIONAL; FORENSIC; RESEARCH

54. **National Quality Standards for Substance Misuse Services**. Good Practice Guide to Service User Involvement. Scottish Government.

    KEYWORDS: STANDARDS; SUBSTANCE MISUSE; SCOTLAND

55. **Wales Substance Misuse Treatment Framework: Service User Involvement Framework.** ?Date c.2008. Includes a seven-rung version of the Involvement Ladder by Susan Lawrence (adapted from Hear By Right/Roger Hart/Arnstein):
    Rung 7: Initiating
    Rung 6: Implementing
    Rung 5: Decision Sharing
    Rung 4: Representation

Rung 3: Consultation
Rung 2: Positive contributions
Rung 1: Information
Appendix 1 is a Checklist for Service User Involvement to evaluate the current level of service user involvement in your work. Covers: Commissioning and Planning Structures / Meetings / Service Providers. This also has a Sample Charter for Service User Involvement which covers:

- Design and Planning of Services
- Personal planning of services (cf. individual care)
- Joint planning and commissioning of services
- Service delivery and monitoring

http://wales.gov.uk/dsjlg/publications/commmunitysafety/submisusetreatframework/usere.pdf?lang=en

KEYWORDS: OPERATIONAL; STRATEGIC; LADDER; CHARTER; CHECKLIST; SUBSTANCE MISUSE; WALES;

56. **Good Practice guidelines to support the involvement of service users and carers in Clinical Psychology Services. Kay Sheldon and Emma Harris (2010)** British Psychological Society Division of Clinical Psychology. This uses four levels of involvement: individual, operational, strategic and evaluative. At each of these levels it uses a 4 colour traffic light system to indicate what stage involvement has reached: red, amber, blue and green. [red=no progress… etc.]. The principles were arrived at through asking clinical psychologists, carers and service users 'what works'; and from applying 'recovery' principles to describe the perspective service users and carers may adopt if afforded more key positions of power in mental health services. The principles are as follows, and closely reflect those we have arrived at through the 4PI framework:

- Ask service users and carers how they want to be involved: establish a culture of partnership, inclusion and openness from the outset.
- Direct experience of mental ill health is valuable and can enrich professionals' knowledge.
- Involvement should be values-led and must be inclusive, equitable, supportive, respectful, transparent and open, acknowledging and valuing diversity.
- Involvement should aim to be service user- and carer-led, for example, determining research/consultation questions rather than simply responding to consultations.
- Power differentials should be acknowledged and participants should strive towards partnership, being service user- and carer-led.
- Consultation is necessary but not sufficient to render an initiative 'involvement'.
- Build links within and outside of the organisation(s) participating.
- Involvement should occur at every stage of an initiative.
- Involvement initiatives should be documented, evaluated and reflected upon so that learning is not lost with feedback on its impact being given at every stage.

- Involvement should be iterative and follow the act – evaluate – reflect – learn-act cycle

This document was found at the following location on 14 July 2014:
www.ispraisrael.org.il/Items/00289/Service_user_and_carer_involvement.pdf

KEYWORDS: OPERATIONAL; GOOD PRACTICE; PRACTICE; CYCLE;

Other service groups: disability, homelessness, children and young people

57. **Tipping Point: User involvement project**. **Becky Rice and Paul Robson. December 2006. RADAR/University of East London**. Research looking at the involvement of disabled people in decision-making of disability organisations. Aim is to promote involvement of disabled people in disability organisations through sharing experience and good practice. Two stages: a survey and 3 case studies. The case studies revealed that high levels of involvement could be achieved by combining **principles, people in key positions** and **practices**. They came up with *10 Tools for Change…*
    - Agree your statement of values
    - Ensure that disabled people work in front-line roles
    - Make many ways to feedback
    - Link personal with political (e.g. choosing priority issues for campaigns)
    - Organise a pool of representatives
    - Act democratically
    - Support the board – i.e. support disabled people as members
    - Tackle governance issues
    - Design leadership
    - Use principles to guide practice (e.g. social model of disability can be foundation for practices that enable people to empower themselves)

    KEYWORDS: OPERATIONAL; GOOD PRACTICE; DISABILITY; STRATEGIC

58. **Hear By Right toolkit with CD**. (**2008) National Youth Agency**. Developed for the involvement of children and young people, these resources appear to be really useful as a model for increasing and improving involvement in organisations, nicely designed. Resources include a Standards framework for the participation of children and young people, a mapping and planning tool, including self-assessment tool for young people to complete. Based on 7 standards:
    - Shared values
    - Strategies
    - Structures
    - Systems
    - Staff
    - Skills and knowledge

▪ Style of leadership

The standards require self-assessment at three levels of performance: Emerging, Established and Advanced. For each standard, there is a commentary, things to think about, and suggested evidence (paper, verbal, observation) – with indicators for what might count as Emerging, Established and Advanced. Finally there are Top ten tips and resources. Using it as a self-assessment tool, organisations can also go for the recognition of a national award at three levels – bronze, silver and gold.
Their resources are available at: www.nya.org.uk/our-services/hear-right/

KEYWORDS: TOOLKIT; CHILDREN/YOUNG PEOPLE; GOOD PRACTICE; STANDARDS; SELF-ASSESSMENT

59. **Service User Involvement: A study into service user involvement in youth homelessness in Scotland. Scottish Council for Single Homeless, 2006**. Includes a mapping tool based on Arnstein's Ladder and two self-assessment grids as well as a mapping tool for methods of involvement. The Service User Involvement Grid involves seven levels of involvement against three 'domains': Evolution (development) / Strategy / Day to Day. The 7 levels are:

▪ Service user control   )
▪ Delegated power   ) degrees of service user control
▪ Partnership   )
▪ Selective involvement   )
▪ Consultation with feedback   ) service user influence
▪ Consultation no feedback   )
▪ Informing   )
▪ Directive.   ) non-participation

Available from the Homeless Action Scotland website:
www.homelessactionscotland.org.uk/uploads/Service%20User%20Involvement%20-%20report.pdf?phpMyAdmin=b26c745cdf2c5e4abfe6e2a241672a9a

KEYWORDS: OPERATIONAL; LADDER; SELF-ASSESSMENT; TOOLKIT; HOUSING/HOMELESSNESS

Level C Strategic: commissioning, leadership

60. **A review of values-based commissioning in mental health – Emma Perry, Jo Barber and Elizabeth England (2013) NSUN**. This is a review of values-based commissioning in the West Midlands. It reports an evaluation of the West Midlands mental health commissioning modelling group, but it also includes consultation data from service users relating to values-based commissioning. Available on the NSUN website: www.nsun.org.uk/assets/downloadableFiles/values-based-commissioning-report--20132.pdf

    KEYWORDS: STRATEGIC; COMMISSIONING; EVALUATION

61. **Engagement in the Commissioning Cycle – Best Practice Guidelines: a reference tool for commissioners. NMHDU/MHIP/Making Space (2011)**. Developed with a steering group of service users and carers. This looks very comprehensive and useful. It provides an 'essential checklist' of eight elements of the commissioning cycle and four simple building blocks for involvement: Clarity; Commitment; Timescale and resources; Feedback. It has a self-assessment tool for commissioners at the end. Note: it includes reference to the MARD guidelines on payment for involvement. www.helplines.org/uploads/1/1/2/5/11258169/engagement_in_the_commissioning_cycle2.pdf

    KEYWORDS: STRATEGIC; COMMISSIONING; GUIDELINES; CHECKLIST; SELF-ASSESSMENT;

62. **An evaluation of mental health service user involvement in the re-commissioning of day and vocational services. London: Centre for Mental Health (February 2010).** This is an interesting report of a process of involving service users in the process of re-commissioning day and vocational services. Relevant for any level of involvement, it includes an honest account of what worked well and what did not work well and gives the following recommendations for what would have improved the process:
    - Greater clarity of purpose
    - More attention to detail
    - More openness on the part of commissioners
    - Processes for conflict management and resolution

    Report available on the Centre for Mental Health website: www.centreformentalhealth.org.uk/pdfs/service_user_involvement_in_recommissioning.pdf

    KEYWORDS: STRATEGIC; EVALUATION; COMMISSIONING;

63. **User Involvement and Consultation**: **Speech, language and communication needs - the Commissioning Support Programme (2011)**. Nicely designed. Calls itself a tool and it does lay out tables as examples for filling in – based on an adapted version of the involvement 'ladder' with five levels: informing, consulting, involving, collaborating, empowering. They use a different version of the Plan - Do - Study - Act cycle: Understand - Plan - Do - Review. Good list of useful resources at the end. Available from the Communication Trust: www.thecommunicationtrust.org.uk/media/12889/slcn_tools_user-involvement1_1_.pdf

    KEYWORDS: STRATEGIC; TOOLKIT; LADDER; COMMISSIONING

64. **Leeds HAZ Service User and Carer Involvement Toolkit: A toolkit for health and social care practitioners working in Leeds localities. July 2001.** Toolkit for involvement in commissioning. Nicely designed - for use by health and social care staff in Leeds. Aims to help in involving service users and carers in service planning and delivery. Guidance on general principles, step by step advice on planning involvement; useful contacts in Leeds. Your approach will depend on What you are trying to achieve, Who you need to involve and What resources are available. This uses a five-rung ladder of participation from Wilcox's Guide to Participation (1994):
    - Information
    - Consultation
    - Deciding together
    - Acting together
    - Supporting independent community interests

    They use this to produce an Involvement Matrix for describing involvement in work activities: these 5 levels against three commissioning categories: Planning / Implementing / Monitoring. There is a blank matrix for photocopying in the Appendix. Essential things to do: Be clear; Be candid; Be considerate.

    This is followed by a step by step guide – questions to think through before involving people starting with 'Why do I need to involve people and what do I want to achieve?' – and a checklist based on 'Think People' 'Think Place' 'Think £s'. Finally there is a brief guide to assessing the outcome of involvement… They suggest identifying the desired outcomes on a long term, medium term and short term scale for all stakeholders at the beginning of the whole process. Available from NSUN resources.

    KEYWORDS: STRATEGIC; COMMISSIONING; TOOLKIT; LADDER; CHECKLIST; EVALUATION

65. **Stronger in Partnership 2: Involving Service Users and Carers in the design, planning, delivery and evaluation of mental health services in Wales** – Adult Mental Health Services. Wales Assembly Government. 2008. *The idea of*

producing the original guidance, including having a 'Charter' and a 'Checklist',
was conceived by a user of mental health services in Wales.
It uses three levels: Planning and delivery of services / Care Planning (interesting as it looks at individual care planning, the CPA and Carers). / Evaluation and Learning. It includes a Charter for Service User and Carer Participation which covers: the Design and planning of services; Service delivery and monitoring; and Monitoring and evaluation. It also includes a Good Practice checklist and monitoring tool.
www.gavowales.org.uk/Health_and_Social_Care/Mental_Health_Development/Consultation_Documents/STRONGER%20IN%20PARTNERSHIP.pdf

KEYWORDS: WALES; STRATEGIC; CHECKLIST; TOOLKIT; CARERS; GOOD PRACTICE; CARERS

66. **Outcomes and Commissioning Project 2007-9 – funded by Bradford and Airedale Teaching PCT and delivered in partnership with the University of Central Lancashire.** This project aimed to improve mental health services for BME communities by enabling them to work together with service commissioners. Over the course of the project, through a cycle that included community research, members drew up a strategy for involvement which aimed to 'hopefully, in the future enable their full involvement in designing and improving services – engaging with BME communities, building their confidence through training and providing on-going support.' Out of this project came the Sunshine Evaluation Tool [also in this resource list], which is a user-led needs assessment tool.

Full project report: Seebohm, P., Thomas, P., Brown, C., James, M., Moore, G., Yasmeen, S. and Haider, A.J. (2009) Outcomes and Commissioning in Mental Health Services for Black and Minority Ethnic Communities: project report 2007-2009. NHS Bradford and Airedale and University of Central Lancashire. Available from: http://mighealth.net/uk/images/5/51/Mhcomm.pdf
Reported in an article in the Life in the Day (now called Mental Health and Social Inclusion): Bhat S, Kaur K, Kauser S (2009) 'Voices for change – involving BME groups in commissioning mental health services'*A life in the day* vol 13 (3) August.

KEYWORDS: STRATEGIC; DIVERSITY; COMMISSIONING; LOCAL

67. **Engagement Cycle *web based tool* – NHS Institute for Innovation and Improvement / Dept of Health / Inhealth Associates 2012**
http://www.institute.nhs.uk/images/Engagement_Cycle/Engagement_Cycle_Overview_PDF.pdf
This document is for commissioners of health services, it is intended to complement the online resource and give an overview of what is required of commissioners when engaging patients, carers and the public in the decisions being made about health service provision.

KEYWORDS: STRATEGIC; COMMISSIONING; TOOLKIT; CARERS

68. **Beyond Consultation: A guide for health commissioners. How staff and service users can work together to improve health services. Panos London and Naz Project London, March 2012.** 'This guide suggests different and practical ways for health commissioners to encourage real engagement between service users and staff so that health services can adequately address the needs of seldom-heard groups. The guide provides lessons from previous experiences of work in this area and outlines key steps in an effective engagement process.'
http://panos.org.uk/wp-content/files/2012/03/Beyond-Consultation-a-guide-for-health-commissioners.pdf

   KEYWORDS: COMMISSIONING; STRATEGIC; DIVERSITY

69. **Involving Users in Commissioning Local Services. Age Concern London 2010 / Joseph Rowntree Foundation.** This study involved seven diverse service user groups and commissioners in six areas of London. The project focused on what was actually happening for them and provides pointers to how user involvement in commissioning could work in practice; these are their recommendations:
    - *Realities of involvement:* e.g. resources, being involved from the start and in sufficient numbers, willingness to explore and make mistakes, honesty.
    - *The need for honesty and feedback:* honesty about user involvement and about commissioning, feedback about what has and has not changed.
    - *Different stages and different contexts of commissioning:* need to spell out the different steps and involve service users in a way that can make a difference.
    - *Involving others:* frontline staff and providers, care workers and others are likely to have a better understanding about what people want and the texture of their lives – their knowledge needs to be valued.
    - *Ownership:* there needs to be ownership of user involvement by all – including public services.

    Summary and full report available from the Joseph Rowntree Foundation website: www.jrf.org.uk/publications/users-local-services

    KEYWORDS: STRATEGIC; COMMISSIONING; LOCAL; DIVERSITY

D Evaluation / monitoring of involvement

70. **Involvometer – developed by Premila Trivedi 2003,** used also in 'Learning from Experience' by Tew et al (2004; updated 2011). Useful model for the self-assessment of how an involvement activity felt for service users/carers but also can feed into an organisation's assessment of same. Based more on process than impact, it has three sections: before, during and after [the involvement activity]. It covers many of the practical issues that make involvement a good or not so good experience – e.g. getting information in advance, knowing why you are involved, feeling listened to, etc. There is also an article by Premila Trivedi in Mental Health Today on the Involvometer (December 2003).

    KEYWORDS: INDIVIDUAL; EVALUATION; SELF-ASSESSMENT

71. **MARD 2007 Valuing Involvement: Monitoring and evaluating service user and carer involvement. Developed by NIMHE North West, 2007**. The tools were developed to enable 'us to compare outcomes of the involvement experience, as well as measure the impact of involving people'. This usefully supports the 4PI framework – or vice versa! – as it proposes a framework across three areas:
    - Accessing involvement, including selection of service users and carers
    - Experience of being involved
    - Impact and outcomes of involvement

    It includes reference to the 'End of Involvement' questionnaire which is included in the Involvement Passport [also in the resource list]. Also includes a Fair Access form, Involvement plan and individual testimonial forms. For assessing impact and outcomes, it suggests a range of approaches:
    - Involvement plans (audit of)
    - End of involvement questionnaire (analysis of)
    - Individual testimonial forms (analysis of)
    - Requests to expand on issues raised – to service users and carers and staff
    - Follow up interviews, follow up questionnaires
    - Staff appraisals
    - Analysis of other achievements…

    Available from NSUN website: www.nsun.org.uk/get-involved/survivor_involvement/

    KEYWORDS: EVALUATION; MARD; TOOLKIT; CARERS

    MARD Valuing Involvement: Involvement Passport. Developed by Rob Hughes and Ian Porter on behalf of NIMHE North West. The involvement passport or portfolio is a means of recording activities, training etc. for service users and carers. Has an end of involvement questionnaire which could be adapted for use. Available from NSUN: www.nsun.org.uk/get-involved/survivor_involvement/

or: www.londonhp.nhs.uk/wp-content/uploads/2011/10/Valuing-Involvement-involvement-passport.pdf

KEYWORDS: PASSPORT; MARD; TOOLKIT; CARERS

72. **SCIE Stakeholder Participation Guide 20 Participation: finding out what difference it makes. 2007.** Commissioned by SCIE and co-produced by service user researchers with a team of researchers from Sheffield Hallam University, ScHARR and Trent. The research pointed very clearly to a gap between the participation of service users and carers (where there has been considerable activity) and the systematic evaluation of what difference this is making (where there has been relatively little). The research came up with nine Big Questions:

1. Why bother to evaluate?
2. What stops us from finding out whether participation makes a difference?
3. What do we mean by making a difference?
4. When do we decide to find out whether a difference is being made?
5. Who says? Who does the evaluating?
6. How do we find out? (methods)
7. What tools and resources do we need?
8. What about differences? (differences of opinion, conflict)
9. What happens next?

It has a checklist of 20 pointers to help your evaluation of service user and carer participation, with items covering issues from purpose through practice and power to implementation. Available from the SCIE website: www.scie.org.uk/publications/guides/guide20/files/guide20.pdf

KEYWORDS: GOOD PRACTICE; EVALUATION; CARERS; CHECKLIST

73. **The DREEM (Developing Recovery Enhancing Environments Measure); Assessing the recovery-commitment of your mental health service: A user's guide for the developing recovery enhancing environments measure (dreem). Ridgeway and Press, 2004.**
The DREEM can be used as an assessment and service/agency self-study, or as an aspect of on-going service evaluation and service improvement efforts. It was designed to be answered by people with mental health problems, who have extensive involvement with the mental health system and are subject to the Care Programme Approach (CPA). See Recovery Devon website for the above reference:
www.recoverydevon.co.uk/download/DREEM%20total%20dft4%20no%20tc.pdf
Also, see: Dinniss et al 'User-led assessment of recovery using DREEM', Psychiatric Bulletin (2007), 31, 124-127.

KEYWORDS: EVALUATION; MEASURE; RECOVERY

74. **Service User Involvement in Redcar and Cleveland's Mental Health Services Svennevig, Julia (2004)..** An evaluation of service user involvement in the Redcar and Cleveland locality with an exploration of factors constraining progress and how these might be overcome. This looks useful. It uses three domains of involvement: involvement in own care planning, in delivery of services, in planning of services. Within that, it looks at three levels: Receiving Information; Consultation and Exercising control. Alongside these it emphasises the importance of *meaning* which service users have identified in terms of feeling valued and the relevance/ownership of the involvement activity. Available from NSUN resources.

    KEYWORDS: EVALUATION; LOCAL; RESEARCH

75. **User involvement in voluntary organisations Shared Learning Group: think-piece on evaluating user involvement. May 2008.** Very interesting read. Available from NSUN resources.

    KEYWORDS: OPERATIONAL; EVALUATION;

76. **NHS R&D Forum Service User and Carer working group: Involvement Portfolio** – developed first developed by the NHS R&D Forum Service User and Carer Working Group in 2008. It was reviewed and revised in April 2014. Developed by and for service users and carers involved in research, it allows for people to fill in themselves; includes reflections on the experience of involvement, as well as a record of involvement activities and a record of training.

    'It is a tool for those using health and social care services who are involved in voluntary or involvement activities such as consultation, committee membership, research and development, to record and provide evidence of their activities. Its use is voluntary and it is up to the individual how they use the portfolio, what they record and how they choose to use it in demonstrating their skills and expertise'. www.rdforum.nhs.uk/content/working-groups/service-user-carer-working-group/

    KEYWORDS: EVALUATION; PASSPORT; RESEARCH

KEYWORDS used

ADVANCE DIRECTIVE
ADVOCACY
ASSETS
BARRIERS
BME
CARERS
CHARTER
CHECKLIST
CHILDREN/YOUNG PEOPLE
COMMISSIONING
COMMUNITY
CYCLE
DISABILITY
DIVERSITY
EVALUATION
FORENSIC
GUIDELINES
GOOD PRACTICE
GOVERNANCE
HOUSING/HOMELESSNESS
IMPACT
INCLUSION
INDIVIDUAL
LADDER
LOCAL
MARD (Making a Real Difference)

MEASURE
OPERATIONAL
OUTCOMES
PARTNERSHIP
PASSPORT
PRACTICE
PRINCIPLES
PUBLIC MENTAL HEALTH
RECOVERY
RESEARCH
RESILIENCE
RIGHTS
SCOTLAND
SELF-ASSESSMENT
SROI (SOCIAL RETURN ON INVESTMENT)
STANDARDS
STRATEGIC
SUBSTANCE M ISUSE
TEMPLATES
TRAINING/EDUCATION
TOOLKIT
USER-LED
WALES
WELLBEING