



Shared Decision Making and Social Inclusion for Citizens/People with mental ill health difficulties

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- Views expressed are those of the authors and do not necessarily represent those of the NHS, the National Institute of Health Research, or the Department of Health
- It is a partnership between Cambridgeshire and Peterborough Foundation Trust and Anglia Ruskin University, including service users, providers, and researchers.



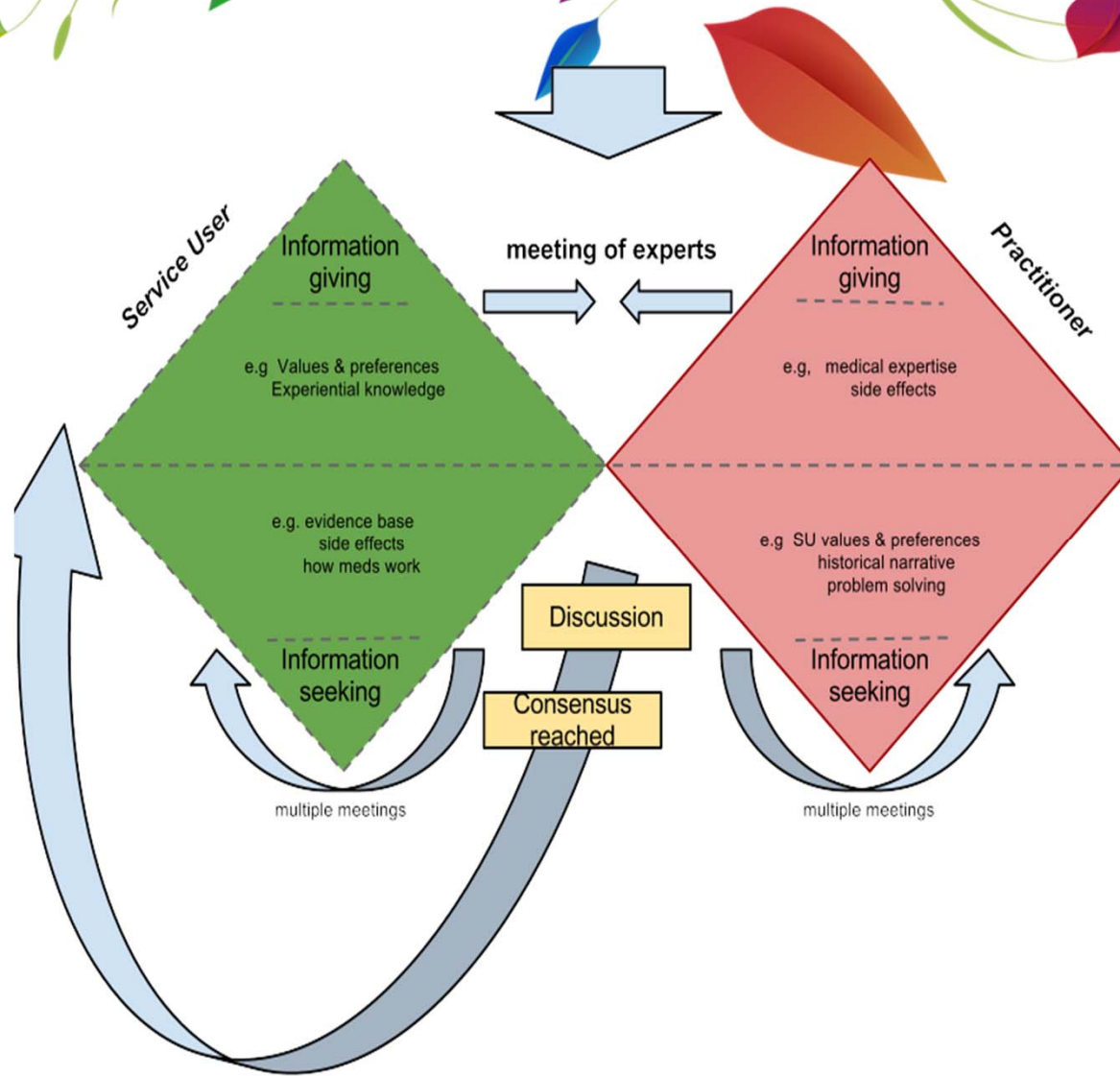
What is SDM?

SDM is a process of sharing information, experience, and preferences, in which the decision is not known in advance.

According to Charles et al Gafni (1999) it entails:

1. the inclusion of at least two people, patient and clinician
2. who share information
3. take steps to build a consensus about preferred treatment
4. reach agreement on the treatment to implement

Deegan, Drake and Rapp (2010) add that the two participants are experts, though in different aspects





- The focus on SDM in primary care has been in existence for sometime, especially around difficult decisions such as in the case of cancer intervention (O'Connor et al, 2006), i.e. where there is a conflictual decision to be made
- Elwyn and his colleagues from Cardiff have developed an observation tool of SDM in primary care in the UK (Edwards and Elwyn, 2009).



The case for SDM in mental health

- Shared decision making is proposed as a means to improve collaboration between clinicians and service users, enhancing the journey of recovery, self management (Schauer et al, 2007) and quality of life (Joosten, 2008)
- Priebe, McCabe et al (2007) have demonstrated the effectiveness of following the patient's agenda in clinical consultations in six European countries.



The case for SDM in mental health

- The Department of Health and NICE are supportive of shared decision making as a way of working in mental health (Nice, 2009, DH 2008, DH 2011)
- They accept that there should not be “no decisions about me without me” (DH 2011)
- The high level of lack of adherence with prescribed psychiatric medication should not be perceived as the patient’s faulty but is due to lack of agreement (Nice, 2009)



Mind's response to Liberating the NHS: No decision about me without me

- Concerns raised that the meaning of SDM is mostly a way of increasing provider choice and SDM definition & linear care pathway described doesn't reflect experiences of service users
- Parity of Esteem should be embedded in SDM, as should personalised care planning, the use of joint crisis care planning, advanced directives and the provision of accessible information
- Greater choice of treatment, self referral routes, consultant teams, psychological therapies and alternatives to hospital.



- How is SDM related to social inclusion?
- Most citizens have the right not to accept decisions made about them without their agreement
- However, in mental health this is often not the case:
- service users' experiential knowledge is devalued, and providers have the power to impose compulsory interventions.



SDM in Psychiatric Medication Management is a problematic issue given that:

- Research evidence highlights that 50% of mental health service users do not:
 - take the medication prescribed for them on a regular basis
 - often do not inform their prescriber of this decision (Nose, Barbui and Tansella, 2003)
- Why do people stop taking medication, given the evidence as to its effectiveness? (Roe et al, 2009)
- The growing doubts as to the efficacy of antipsychotic medication (Morrison et al, 2012)



Existing Evidence

- SDM in an admission ward within an RCT design (Hamann et al, 2006). People with Schizophrenia, able to make decision, no harm, does not require more time than the usual consultation, had no impact on clinical outcomes ; one off intervention, 18 month follow up
- Loh et al (2007a and 2007 b) SDM in primary care for people with depression; also RCT design, and also in Germany: able to make decisions, no harm, increased satisfaction among patients, no impact on clinical outcomes, does not require more time. One off intervention.



Existing Evidence

- SDM systematic review of RCT studies (Joosten et al, 2008 vs. Duncan et al, 2010) RCT studies exist (US, Germany) SDM is effective for some people with Schizophrenia and with Depression, the need for more research with less loss in follow up.
- Soteria (Calton et al, 2008) : residential therapeutic community with minimal, or no use of medication (US and Switzerland)



Existing Evidence

- The Open Dialogue approach (Seikkula et al, 2011) : exercising SDM not only with the index patient but also with family and neighbours for over 10 years in Finland: high rate of recovery, minimal use of medication; those without medication do better, reduction in the prevalence of new cases of Schizophrenia
- The lessons from the longitudinal studies on recovery from Schizophrenia pertaining to psychiatric symptoms and medication (Harding and Zahinster, 1994, Harrow and Jobe, 2007)



Existing Evidence

- The lessons from the Hearing Voices Network (Australia, The Netherlands, the UK) (Romme et al, 2011)
- Training 100 staff members in West London to apply the HVN approach (Dec 2012) (Prof. Steve Trenchard)



Experimental projects of SDM

- (Deegan and Drake, 2006, Deegan et al, 2008, Deegan et al, 2010)
- Systematic use of simple tools
- Being supported by peers
- Use of electronic means (www.patdeegan.com/commonground)
- Use of the concept of Personal Medicine (Deegan, 2005)



The ShiMME project focuses on the process of shared decision making in psychiatric medication management in order to:

- Create a more collaborative partnership between service users and prescribers in an area of central importance to mental health services
- Enhance active participation of adult service users who have experienced psychosis
- Use of tools developed as aid to SDM in practice



- **Phase 1** - A literature scoping review and a wide-ranging consultation exercise across the Trust about the content of the training programmes . Completed **September 2011**.
- **Phase 2** – Delivering the training programmes, based in Rehabilitation and Recovery Services, accompanied by a before and after rigorous evaluation of their impact. **April 2012 to March 2013, follow-up begins in July 2013.**



Evaluation

- Key dimensions: processes and outcomes
- Primary outcome: reduction in conflictual decision making
- Tools: Conflictual decision making scale, Option, CSSRI, Recovery star, Attitudes to Drugs Taking.
- Cost effectiveness analysis



Demographic data

- 48 service users took part in the training programme
- Age: 35-44 45-54
- Gender: 26 were males, 22 were females
- Education: 61.7% to tertiary level
- White, British



Psychiatric background

- 63.8% had 15 years experience of mental ill health
- Diagnosis: Schizophrenia: 16 Depression: 13
- Bipolar: 10
- 35% had multiple diagnosis (average: 3)
- 29.8% felt decision was joint; 63.8% felt they would like it to be a joint one at the pre-prog phase.



The Challenges to be faced

- Meeting of two different types of knowledge or gap in knowledge?
- Accessing and understanding information about psychiatric medication
- Sharing power between unequal partners to SDM



- We conducted 7 consultation groups: 4 with service users (27 participants in total), and one each with psychiatrists, CPNs and care co-ordinators (26) between July and September 2011. All from the R&R services in Cambridge
- Each group meeting lasted 90 minutes; interactive discussion methods were applied



Each discussion group focused on;

- Current prescription and medication management practices
- Levels of service user involvement
- Satisfaction with existing practices and preferences for change
- Examples of innovative initiatives to foster shared decision making
- Identification of obstacles and opportunities to do with SDM
- Participants' ideas for content and format of the training programmes



All groups were in favour of SDM, but aware that it is not really implemented at present. Perceived **barriers** to achieving it included;

- Assumed difficulties people would have making decisions during an acute episode of mental illness
- Fear of risk if the wrong decision is taken
- Lack of good enough information
- Readiness to let prescribers decide on their own
- Not having a trusting relationship



What can facilitate SDM?

- Providing good enough information
- Learning to weigh the information
- Feeling listened to
- The importance of good relationships
- Taking seriously what the person has to say
- Involving the care co-ordinator, family members, and friends in the process of SDM



The training programmes

- All training programmes focus on the process of SDM, we do not provide advice on medication to any individual.
- For R&R staff in Cambridge, Huntingdon and Peterborough.
- Programmes were delivered in small, interactive, groups



The training programmes

- Why parallel programmes?
- Trainers: co-leads: a service user trainer and a professional providers (2 psychiatrists, one CPN senior nurse)
- Duration: psychiatrists: two sessions of two hours each, Some self study, using the SHIMME website.
- Care co-ordinators: three sessions of 90 minutes each
- Service users: 4 meetings of 2.5 hours each+follow up meeting



Content : providers

- What does SDM mean in the context of mental health services?
- The process of SDM
- Knowledge of research evidence, including of alternatives to medication
- Critical issues in managing psychiatric medication in collaboration with service users
- Systematic use of feedback forms (one from the patient, one from the psychiatrist) in consultation meeting with service users



Content: service users

- The process of SDM
- Knowledge of key research evidence, including of alternatives to medication
- Critical issues in managing psychiatric medication in collaboration with service users
- Systematic use of feedback forms (one from the patient, one from the psychiatrist) in consultation meeting with service users
- Constructive assertiveness training



Content: service users

- How to articulate one's preferences re medication: benefits vs. adverse effects
- Where to find reliable information and how to evaluate it
- Learning to systematically share one's experiences of taking medication and preferences with one's prescribing psychiatrist
- Sharing experiences and preferences with care co-ordinators, support staff, peer support workers



Content: service users

- Developing a wellbeing plan, focused on personal medicine
- Becoming aware of alternatives to medication



Sample

- 15 psychiatrists
- 35 care co-ordinators
- 48 service users
- Difficulties in recruitment



Experience of being a service user trainer

- Gained confidence
- My contribution and experience was genuinely appreciated
- Felt valued
- Working with a professional colleague as an equal was a refreshing experience
- Learnt more about the difficulties that professionals face



Participants' experience

- Pre-conceptions were challenged
- Positive learning experience
- Time was ring-fenced away from the pressures of work
- Stimulated thought and discussion around everyday challenges
- Opportunity to have frank discussions in a safe environment



Service users feedback

- *'Very interesting with lively talk and shared involvement'*
- *'This was something I wish was in place 20 years ago, hopefully this will help people in the future'*
- *'I have discussed nearly everything that does concern me, it was enjoyable and interesting'*
- *'It will be easier to talk to my psychiatrist about changing my medication'*
- *'You listened to our opinions, especially with the service user feedback form'*
- *'Very well presented and very inclusive of each member of the group'*
- *'I hope I will feel more able to make the decision with the psychiatrist regarding my medication'*
- *'Personally, very useful and empowering'*



Where are we now?

- Implementation of ShIMME procedure in everyday R&R practice, updated feedback forms
- Support networks
- Post programme evaluation
- Struggling with the impact of the latest reorganisation on staff morale and on their readiness to engage in a project like ours
- First publication



References

- Charles, C., Gafni, A., Wealan, T. 1999 Decision-making in the physician-consumer encounter : revisiting the shared treatment decision-making model. *Social Science and Medicine*, 49 :651-61
- Calton T, Ferriter M, et al (2008) A systematic review of the Soteria paradigm for the treatment of people diagnosed with schizophrenia. *Schizophrenia Bulletin.*, 34: 181–192
- Cooper C, Bebbington P, et al (2007) Why people do not take their psychotropic drugs as prescribed: Results of the 2000 National Psychiatric Morbidity Survey. *Acta Psych. Scand.*, 116: 47-53
- Curtis, L.C., Milstrey Wills S, D.J., Penney, S.S. Ghose, S.S., Mistler, L.A., Noahone, I.H., M. Delphin-Rittmon, Del Vecchio, P., Lesko, S. (2010) Pushing the Envelope: Shared Decision Making in Mental Health. *Psychiatric Rehabilitation Journal* 34, 1, 14-22
- Day J, Bentall R, Roberts C et al (2005) Attitudes towards antipsychotic medication: The impact of clinical variables and relationships with health professionals. *Arch. Gen. Psychiatry*, 62: 717-724



References

- Deegan, P.E. (2005) The Importance of personal medicine: A qualitative resilience in people with psychiatric disabilities, *Scandinavian Journal of Public Health Services*, 66, 29-35.
- Deegan, P.E., & Drake, E.R. (2006). Shared decision making and medication management in the recovery process. *Psychiatric Services*, 5: 1636-1639
- Deegan P, Rapp C, Holter M, Rieffer M (2008) A program to support shared decision making in an outpatient psychiatric medication clinic. *Psych. Services*, 59: 603-605
- Deegan, P. (2010) A web application to support recovery and shared decision making in psychiatric medication clinics. *Psychiatric Rehabilitation Journal*, 34, 23-28
- Dept. of Health (2008) *Medicines Management: Everybody's Business*. DH: London
- Dept. of Health (2011) *Liberating the NHS: Choice and Control*. DH, Choice Team.
- Drake, R., Deegan, P., Rapp, C., (2010) The Promise of Shared Decision Making in Mental Health. Guest Editorial. *Psychiatric Rehabilitation Journal*, 34, 1, 7-13.

Consent Form

Project Name (if applicable) RAISE

I consent to the following use of the video recording either in its entirety or an extract of (this includes the images, sound and transcript):

Please tick

My name being included with my image and voice.

YES NO

This film will be used in the e-learning European MSc in Recovery and Social Inclusion, both during the development of the curriculum and in the future delivery of the course.

YES NO

The University will inform you and seek further permission if the use of the video recording changes.

I understand that I am free to withdraw my consent for use of the video recording at any time, without giving a reason.

Signature _____

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- Duncan, E., Best, C., Chichester: John Wiley
- Edwards A & Elwyn (Oxford
- Hamann J, Cohen R, treatment? Amer. J.
- Hamann, J., Cohen, I treatment. Journal o
- Harding, C.M., Zahni Acta Scandinavica Ps
- Harrow M & Jobe T (medications: A 15-ye
- Joosten E, DeFuentes treatment adherenc
- Kaminskiy, e. Ramon Walker, S. (ed) Mode

health conditions (Review) .

ent choice. (2nd ed). OUP:

isions about their medical

ermoutcome in schizophrenia

n implications for Treatment.

on antipsychotic

aking on patient satisfaction,

tion Management. In:

Publishing, 33-48.



References

- Loh, A., Simon, d., Wills CE Kristen,I., (2007a) The effects of a shared decision-making intervention in primary care of depression: a cluster-randomised controlled trial. *Patient Education and Counselling* 67, 324-32
- Loh, A. Leonhard, R., Simon, D., Wills, CE., ., Harter, M. (2007b) The impact of patient participation on adherence and conical outcome in primary care of depression. *Patient Education and Counselling*, 65, 69-78.
- Malpass, A., Shaw, A., Sharp, D., Walter, F., Feder,G., Ridd, M., Kessler, D. (2009) “Medication career” or “Moral Career”? The two sides of managing antidepressants: A meta-ethnography of patients’ experience of antidepressants. *Social Science and Medicine*, 68, 154-168.
- Morrison, A.P., Hutton, P., Shiers, D, Turkington, D. (2012) Antipsychotics: Is it time to introduce patient choice? *British Journal of Psychiatry*, 2011, 83-84.
- NICE (2009) *Medicine adherence: Involving patients in decision about prescribed medication and supporting adherence*. London: NICE



References

Nose, M., Barbui, c. Tansella, M. (2003) How often do patients with psychosis fail to adhere to treatment programmes? A systematic review. *Psychological Medicine* 33, 1149-1160.

O'Connor, A.M., Bennett, C.L. Stacey, D., Barry, M., Col, N.F., Eden, K.B. (2006) Decision aids for people facing health problems or screening decisions. *Cochrane Database of Systematic reviews*, issue 3.

Priebe, S. McCabe, R., Bullenkamp, J. (2007) Structured patient-clinician communication: 1 year outcome in community mental health care: Cluster Randomised Control Trial. *British Journal of Psychiatry*, 191:420-422.

Roe, D., Goldblatt, H., Balush-Klienman, V., Swarbrick. M., &

Davidson, L. (2009). Why and how people decide to stop taking prescribed psychiatric medication: Exploring the subjective process of choice. *Psychiatric Rehabilitation Journal*, 33(1), 38-46.