

# Recovery and Independent Living Professional Expert Group (R&IL PEG) Advisory Paper 8

## Recovery orientated prescribing and medicines management

The role and value of medication as a support for recovery is particularly problematic in psychiatry.

People who come to psychiatric services are very frequently offered medication and yet the people taking it often feel they have little choice or control and the use of medication is frequently accompanied by ambivalence and many negative associations. It is also commonly taken / used erratically and 'non-compliance' is considered a major reason for relapse and recurrence. This guidance paper reviews the implications of considering our practice around the offer of medication, and sometimes the requirement to take it, in the context of the values and principles of recovery-focused relationships and services and suggest ways in which we may reconsider and review our practice.

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## SUMMARY AND RECOMMENDATIONS

The aim of this paper is to provide guidance for mental health workers in putting recovery principles into practice in relation to prescribing and medicines management. The following recommendations are based on three sources of information about the use of medication to support personal recovery: a review of published literature, a survey of the experiences of people in Devon who take medication for mental health reasons, their supporters and mental health workers and the discussions of the project group.

### **What is the role of medication in recovery?**

- Medication can have an important role in recovery but as recovery is a unique, individual process, the role of medication will be different for each person.
- Medication should be thought of as a tool that a person can choose to use to help them achieve their personal recovery goals.
- Many people find it helpful to use medication as a way to achieve stability, which can then be a foundation of a recovery process that involves many other tools, activities and relationships.
- Although people may not define their difficulties as being due to illness, they may still find the effects of medication helpful, e.g.: to keep them calm or help them sleep
- Medication can interfere with the recovery process through unwanted effects that can prevent the person making use of other tools, activities and relationships.
- Adverse and unwanted effects of medication can sometimes be worse than the problem they are intended to relieve and there is a need for the person using medication to come to a balanced view weighing up benefits and costs in making medication choices.
- In rare and unusual circumstances it may be judged necessary for someone to be given medication against their wishes within the legal framework of the Mental Health Act. This may be an attempt to manage overwhelming difficulties or distress that are preventing the person from engaging with strategies to address these difficulties or to ensure safety, but the act of doing so can be traumatising and often adds to the problems of achieving personal recovery. There is no simple resolution to concerns about the use of compulsory medication in the service of recovery for people who lack capacity and all involved will need to struggle to reconcile these contradictions and costs in our best efforts at care and treatment.

### **What can all mental health workers do?**

- Be aware that many people do not feel able to be honest about their experience of medication because they fear the consequences. They may need time to build trust and support and coaching to feel able to start actively participating in prescribing and medication management processes.
- Support hope by giving the message that people can take control of how they use medication and sharing recovery stories from people who have reduced medication, used it in a targeted way, found other ways to manage their difficulties or recovered to the point where they no longer needed it.
- Explore people's experiences of taking medication, how it has made them feel, the impact it has had on their lives, whether it supports their personal goals and the meaning for them of taking medication. Where people express concerns, take them seriously and explore ways of addressing them.
- Explore people's preferred way of understanding their difficulties and how medication fits with this, identifying other strategies and therapies that might be more acceptable to the person.
- Discuss the ways in which medication could support someone in achieving their personal recovery goals, e.g. through improving sleep, helping them feel calmer, without necessarily framing it as a treatment for an illness.
- Support people in getting and understanding adequate information about medication and the possible risks and benefits for them. Encourage them to find a range of sources of information, including personal accounts of using medication as well as the results of research and manufacturers' information. Support them in understanding that there are limitations and biases to all sources of knowledge about medication.
- Support people to connect with peers around their experiences of using medication. People may be willing to share their own experiences with others who are thinking about trying the same medication. In some settings, formal sessions or groups could be organised. Workers can also share their own experience of using medication, either for mental health reasons or to manage other long term conditions.
- Support people to access mental health workers with particular expertise in medication, such as pharmacists or consultant psychiatrists, so that they have the opportunity to talk in person with someone about their concerns or questions.
- Support people to prepare for meetings with prescribers, encouraging them to identify concerns and questions in advance and think about

ways to make sure they communicate them effectively (possibly through having a supporter present).

### **What else can prescribers do?**

- Adopt a shared decision making approach to prescribing, making people aware of all the options available and weighing up with them the costs and benefits for them of using or not using these medications.
- Give people the opportunity to think about the options and ask questions, possibly over several meetings.
- Respect the choices that the person makes about whether and how to use medication, being clear about the circumstances under which it will no longer be possible to respect their choices, e.g.: where there is an unacceptable risk of harm to the person or others around them.
- When a person chooses to start, stop or change dose of their medication, treat this as a collaborative experiment. Agree with them what it is hoped that using the medication will achieve, identify ways of monitoring how the change in medication has affected them and agree what action will be taken if the change is unsuccessful.
- Consider introducing a simple measuring scale or developing one with the person taking the medication as a way of keeping track of experience over time and providing a basis for discussing the merit and results from taking it.
- Talk with the person about whether it would be helpful to involve their informal support network in making decisions about their medication and monitoring how any changes affect them.

### **What if the person is unable to make choices for themselves?**

- Help people to be prepared for this possibility by agreeing with them in advance about the signs that they are no longer able to make choices for themselves and how they would like workers to respond. Encourage them to develop a WRAP plan, advance directive or other form of crisis plan. Make sure that this is recorded and communicated to the people who are likely to be involved when a person has a crisis.
- Although people may have difficulty making choices when they are experiencing a crisis, they should still be involved in decisions about medication as far as possible. They can be supported to understand the concerns, given information about possible options, asked what they would find helpful, and given some degree of choice, although this may be from a more restricted range of options.

- Try to find someone who can act as an advocate for the person, possibly a member of their informal support network who may also remember what the person has found helpful in the past.
- If compulsory treatment becomes necessary, be clear about why there are concerns and why medication is necessary to address those concerns. Also be clear about how it can be demonstrated that the concerns are resolved and compulsory treatment will no longer be necessary. Offer people the same information, support and opportunities for discussion and exploring other strategies that would be given at other times, allowing people to express their feelings about receiving compulsory treatment.
- Following the crisis or period of compulsory treatment, discuss the action that was taken with the person and how this can inform how they use medication and manage crisis in the future.

# THE RECOVERY ORIENTATED PRESCRIBING AND MEDICINES MANAGEMENT PROJECT

## **Background and context**

The recovery orientated prescribing and medicines management project was commissioned by the Recovery and Independent Living (R&IL) Professional Expert Group in October 2008 as part of the process of revising the R&IL Policy Implementation Guide (PIG). The PIG is intended to be a tool to support putting recovery principles into practice in a range of areas, including prescribing and medicines management. The aim of the project was to produce guidance for people working within the R&IL functions, specifying recovery orientated practice in supporting people to use medication to manage their mental health and their informal supporters / carers. This guidance will build on that provided by the recovery co-ordination PIG, in relation to medicines management as part of the recovery co-ordination role.

For the purpose of the project, recovery principles were taken to be those specified in the Recovery Guide to Practice and Standards, endorsed by the Devon and Torbay Local Implementation Team. These are shown in Figure 1 below.

## **Project process**

A project steering group was formed consisting of representatives from the key disciplines involved in the prescribing and administration of medication (pharmacy, medicine and nursing) as well as a person with lived experience of using medication and mental health services and a person who had experience of the carer role. Membership of the steering group is shown in Appendix 1. The steering group met on a monthly basis between December 2008 and June 2009.

The steering group identified three possible sources of supporting information for developing guidance: a review of the relevant literature, a wider consultation with people who use services, their carers and mental health workers and drawing on their own experiences of putting recovery principles into practice to attempt to operationalise recovery in relation to prescribing and medicines management. Common themes emerging from all these sources of information were identified and synthesised into the recommendations above.

Figure 1. Values and principles from the Recovery Guide to Practice and Standards

## Recovery in practice means:

### Working to *values* which support recovery such as:

- Hope
- Diversity
- Choice
- Meaningfulness
- Acceptance
- Inclusion
- Citizenship
- Partnership working
- Mutual respect
- Empowerment
- Person-centred
- Believing in people

### Working with *principles* which support recovery such as:

- Recovery is about building a meaningful and satisfying life, as defined by the person themselves, whether or not there are ongoing symptoms or problems.
- Recovery represents a movement away from focusing solely on pathology, illness and symptoms to health, strengths and wellness.
- Hope is central to recovery and can be enhanced by people discovering how they can have more active control over their lives and by seeing how others have found a way forward.
- People are encouraged to develop their skills in self care and self management in whatever way works for them. There is no 'one size fits all'.
- The helping relationship between clinicians and patients moves away from being expert/patient to mentoring, coaching or partnership on a journey of personal discovery. Clinicians are there to be 'on tap, not on top'.
- Recovery is about discovering and often re-discovering a sense of personal identity, separate from illness or disability
- People do not often recover in isolation. Recovery is closely associated with being able to take on meaningful and satisfying social roles and participating in local communities on a basis of equality.
- Words are important. The language we use and the stories we tell have great significance to all involved. They can carry a sense of hope and possibility, or be associated with a sense of pessimism and low expectations, both of which can influence personal outcomes.
- The development of recovery-based services emphasises the personal qualities of staff as much as their formal qualifications or professional skills. Training support and supervision aim to cultivate their capacity for hope, creativity, compassion, realism and resilience.
- Family and other supporters are often crucial to recovery and they should be included as partners wherever possible. However, peer support is central for many people in their recovery.
- There will be no more 'them and us', only 'us' - sharing struggles and challenges as part of being human

## **Literature review**

There is little published literature on recovery based practice in relation to prescribing and medicines management: a search of healthcare databases, the internet and recovery policy documents identified six papers in peer reviewed journals (Deegan, 2005, Deegan & Drake, 2006, Deegan et al. 2008, Mead & Copeland, 2000, Noordsy et al., 2000, Roe & Swarbrick 2007), a book chapter summarising some of these papers (Amering & Schmolke, 2009) an outline of how medication should be used in accordance with recovery principles on a service user empowerment website (Deegan, 1995) and a report of a Rethink project on the lived experience of recovery, which included a section on medication (Rethink, 2009). Within the wider context, there is currently a growing emphasis on providing information, choice and involvement in decision making for all people using healthcare services and taking medication, including a move towards personalising medicines management (NPC, 2008), the publication of a NICE guideline on involving patients in decisions about prescribed medications (NICE, 2009) and the launch of a choice and medicines toolkit to support the choice agenda (NIMHE/UKPPG, 2008). The right to informed choice is also enshrined in the NHS Constitution (DoH, 2009). Specifically in relation to mental health, the NICE guidance on schizophrenia (2002, 2009) recommends that the choice of anti-psychotic medication should be made jointly by the service user and healthcare professional, leading to a recent Royal College of Psychiatrists conference on the theme of choice and schizophrenia. There is also support for enabling people to make informed choices in the Department of Health consultation document "New Horizons: towards a shared vision for mental health" (2009), which identifies the use of "information prescriptions" as an example of good practice. Within mental health, there has also been growth in the provision of alternatives to medication, including the development of social prescribing schemes, such as exercise on prescription, prescription for learning and arts on prescription (CSIP, 2009) and the introduction of Improving Access to Psychological Therapy. These developments are all consistent with recovery values.

There is, however, a continuing discourse about the need for people who are diagnosed with severe and enduring mental health problems to take their medication as prescribed. Recommendations from homicide enquiries frequently include strategies for monitoring compliance with medication (University of Manchester, 2008) and the latest revision of the Mental Health Act (2007) has increased the power of mental health professionals to return people to hospital when they are non-compliant with medication in the community. In this context, the aim of medication management interventions is often to improve adherence (e.g. the medication management training course currently run by the Institute of Psychiatry). Such interventions are clearly intended to benefit the person taking medication. However, they are not entirely consistent with a recovery orientated approach to prescribing and medicines management, as described in much of the recovery literature. Deegan (1995) states that while improved adherence is a likely outcome of a recovery orientated process, the aim is for people to experience power and control in relation to their use of medication. An exception is Roberts and

Dorkins (2008), who argue that insisting that someone accepts medication can be paradoxically supportive of recovery, by enabling control of symptoms and associated risk, thus facilitating a return to a meaningful and satisfying life. Their co-authors, writing from the perspective of a lived experience of enforced medication, qualified this by emphasising a need for exploration of personal experiences of taking medication and the meaning of symptoms. Copeland and Mead (2008), in their commentary on the paper, also suggested that workers should engage with the person on reflecting on what had been helpful to them in their recovery and what the person would need to continue moving ahead.

Those authors who have written about medication from a recovery perspective have formulated it as one tool among many that an individual may actively choose to use in pursuit of their personal recovery goals. The role of the mental health worker is to support people in making choices about whether and how best to use medication and other strategies for managing their difficulties.

In describing the experience of people who take medication, Mead and Copeland (2000) identify how unpleasant side effects can compromise quality of life and how many people fear possible long term side effects that have not yet been discovered. In a qualitative study of the relationship between resilience, recovery and medication, Deegan (2005) found that medication could interfere with peoples' use of "personal medicines": self-help strategies that people had found to manage distress and unwanted experiences and improve well-being. Participants in the Rethink project (Rethink, 2009) felt that medication had played a significant role in their recovery but many had also experienced negative effects, which had outweighed the benefits. They wanted to be given more support with self-managing their difficulties and to explore alternatives, such as talking therapies. These authors also described how people had found it difficult to discuss their concerns about medication or the use of alternatives with mental health workers. They felt that they were not taken seriously or that it could lead to pathologisation of their experiences or threat of involuntary treatment. They concluded that people need to be given choices about how to manage their difficulties and responsibility for the consequences of those choices, being allowed "the dignity of risk and the right to failure" (Deegan,1995). However, Roberts et al. (2008) argue that there is a need to balance choice with contextual constraints and that to allow choice where a person lacks capacity to responsibly take constructive risks would be to undermine the recovery process.

Shared decision making has been identified as an approach to prescribing that supports recovery values (Deegan & Drake, 2006, Noordsy et al., 2000). This model has been developed in the management of long term medical illnesses and is described as "laying out all the treatment options, describing the advantages and disadvantages of each, identifying the prescriber's recommendations and rationale for reaching them and then trusting patients to choose their treatment as informed consumers" (Noordsy et al., 2000). Additionally, the expertise of both parties in the decision making process is recognised: the worker in relation to scientific literature and clinical experience

and the person taking medication in relation to their subjective experience and personal preferences. Within the shared decision making process, the worker and the person taking medication can be thought of as co-investigators in an open experiment to see how the chosen medication will affect the individual (Deegan & Drake, 2006).

In order to be active participants in the decision making process, people who take medication will need a range of supports. These include being given, and supported in understanding, information about medication provided by pharmacists and manufacturers as well as hearing from others about how medication has affected them (Deegan & Drake, 2006, Roe & Swarbrick, 2007). In order to promote hope, which is central to recovery, people should not be told that they will have to take medication for the rest of their lives but should be given the message that different people find different strategies useful at different times in their life (Deegan, 1995). Mental health workers can give people information from longitudinal studies, as well as their clinical experience that show that recovery is possible (Noordsey et al., 2000).

People may also find it useful to use decision making aids (Deegan & Drake, 2006) and to find ways of monitoring the impact of medication on their well-being, such as daily ratings of symptoms and side-effects, that can also be contributed to by supporters (Deegan 1995). Mental health workers can support people in encouraging them to ask questions about their medication (see Figure 2) and to prepare for appointments with prescribers, through drawing up an agenda with goals and questions, arranging for an advocate to be present or role playing in advance (Roe & Swarbrick, 2007). Mental health workers can also support people in learning to use other coping strategies for distress and unwanted experiences and other “personal medicines” that enhance their well-being, such as exercise, diet, art, work, relationships or spirituality. They can explore with people how these strategies might interact with prescribed medication and ways that they can be combined for the greatest benefit.

Deegan et al. (2008) describe an evaluation of a peer run Decision Support Centre, established to support shared decision making practice. People attending for medication appointments were given 30 minutes in the centre before meeting with their prescriber, where they received support from peers in using a computer program to hear personal accounts of recovery, reflect on their “personal medicines”, rate their symptoms and functioning since their last visit, report how they had been using their medication, and to identify common concerns and goals for their meeting with the prescriber. Their responses were then forwarded electronically to the prescriber and the report was reviewed in the consultation. Decision making aids (such as a balance sheet of costs and benefits) were then used to make shared decisions about how the person would use their medication, or other strategies they had identified. The centre also provided informal peer support and access to information about medication via the Internet. The evaluation consisted of focus groups with medical practitioners working at the clinic and clients. Medical practitioners felt that clients were able to communicate more effectively about their concerns so that they were able to be more actively involved in the

prescribing process, as well as giving practitioners a more holistic understanding of the clients' needs. Clients also felt that their concerns were more likely to be heard and found it useful to be able to track their progress.

In recommending shared decision making as an approach, there has been recognition that people who use medications may not always have the capacity to make decisions for themselves. Concerns have been raised that it is irresponsible to give people choices when they are lacking in capacity, described as leaving people to 'rot with their rights on' (Davidson *et al*, 2006). Noordsey et al. (2000) emphasise the importance of being clear with people from the outset about such limitations and how they can be addressed. The use of psychiatric advance directives is one strategy that has been identified to ensure a person's continuing involvement in treatment decisions (Deegan & Drake, 2006). Even in the absence of such an agreement, people can still be encouraged to understand and participate in treatment decisions, even if their capacity is impaired (Noordsey et al., 2000). This can include continuing to offer some choices albeit from a restricted range of options (Roberts et al., 2008).

Figure 2. Common questions for consumers to ask during medication meetings with mental health providers (from Swarbrick & Roe, 2007)

- What am I really like when I am off these medications?
- What is the "real me" like now?
- Is it worth taking these medications?
- Are there non-drug methods I can learn to reduce my symptoms, instead of using medications?
- Will my needs for medications change over time?
- What are the long-term studies on the medications, and if there are no studies, what are the risks of not knowing the long-term effects?
- Could I become addicted to these medications?
- Could long-term use of these medications result in memory loss or decreased cognitive function?
- Exactly how will I know if a medication is working for me?
- How long will it be before I should start to notice an effect from this medication?
- What are the unwanted effects or side effects associated with this medication?
- What should I do if I experience side effects?
- Whom can I contact if I have questions or concerns?

### **Operationalising recovery principles**

The following is a summary of the discussions of the project group in attempting to describe practice in relation to prescribing and medication that would be consistent with the principles specified in the Devon Recovery Guide.

### **Role of medication**

Medication has a role in the recovery process, although the nature of that role is likely to vary considerably between individuals. Medication can enhance someone's ability to live a meaningful, contributing life but it needs to be used in such a way that it does not impact unduly on this ability. Medication should also be seen as one of a range of strategies that someone can use to manage their difficulties and should be offered in combination with other interventions that build on an individual's strengths and serve to improve their overall wellbeing.

### **Personal goals**

Medication should be used in support of people's personal recovery goals. For example, for some people, symptom eradication may not be the most desirable goal. There should be discussion about what the person hopes to change or achieve and what role medication could play. This discussion should also include the limitations of the medication in helping people achieve their personal goals.

### **Hope**

In order to support hope, people should not be given the message that they will have to take medication for the rest of their lives. Recovery should be seen as a continuing process and people may find it helpful to use medication at different stages in that process. It is possible for many people to use less or no medication when things are going well and it may be helpful to share stories with the person taking medication where others have been able to take active control of whether and how they use medication. However, taking medication is not a sign of failure and expectations that people will be able to stop taking it can also be unhelpful. The role that medication is playing or could play in each individual's recovery should be regularly reviewed with them, taking account of their personal preferences and stage on their recovery journey, as well as relevant guidance and evidence on the role of medication for people with similar difficulties.

### **Equal partnership, shared decision making and personal responsibility**

People who take medication and mental health workers should be considered to be equal partners in making decisions about medication, although each will bring different knowledge and experience to that partnership. For workers, this will principally be based on scientific theories, evidence from published research and associated guidelines and clinical experience. When working with people with long term difficulties this may include considerable experience of the person themselves. For people taking medication this will principally be based on their personal understandings of their difficulties, how these operate in the context of their lives and their ideas and experiences of what is helpful to them. They may also have obtained published information about medication independently, from contact with peers and support organisations. Making decisions about medication should be a collaborative process in which all these sources of knowledge are represented and valued. There should be an ongoing dialogue in which there is negotiation around whether the person could benefit from medication, which medication would be

most suitable for that individual, how that person can use that medication to best effect within the context of their life, whether the chosen medication is continuing to be of benefit after a period of time and the ways in which any changes to prescribed medication should be made. People taking medication may find it useful to systematise their knowledge and to self-monitor their experiences to inform this process. A Wellness Recovery Action Plan could be used in this way, as it gives a personalised baseline and list of early warning signs. Someone might also wish to use simple numerical rating scales to evaluate the effect of medication.

The NICE guideline on medicines adherence provides evidence based guidance on shared decision making and this guidance should be followed by prescribers and mental health workers supporting people in making decisions about medication. However, this guidance should be considered necessary but not sufficient for recovery orientated prescribing practice.

The guidance recommends:

1. Establishing good communication between healthcare professionals and people who use services, having an awareness of the individual communication needs of each person.

Creating an atmosphere in which people can communicate openly about their mental health difficulties and concerns about medication will require workers to listen respectfully and take the person's experiences seriously. This is likely to take time and may need to happen over the course of several meetings. Certain situations, for example ward rounds, mitigate against this and should not be the only opportunity that people have to meet and talk with their prescriber.

2. Increasing patient involvement, through exploring the balance of likely benefits and risks of using the proposed medicines, accepting that people may prioritise certain risks or benefits in different ways and that on this basis they may decide not to take or to stop a medicine that is being recommended. Healthcare workers should accept that patients have the right to make this decision, as long as they have the capacity to do so.

Within a recovery framework, it is important that people are given responsibility to make decisions about whether to use medication, having been supported in weighing the likely consequences, for themselves and the people around them. It is important in communicating openly about this to make people aware that there are some limitations on their ability to make choices, especially where there are concerns about public safety.

There is often a perception of a simplistic relationship between not taking medication and dangerousness or irresponsibility. It is important to recognise that the relationship between distress and dangerousness is multifactorial and factors which are or may not be responsive to medication, such as age, gender, economic deprivation, social circumstances, substance misuse, anger and personality make a significant contribution to risk. Medication can help to

manage emotional responses and therefore risky behaviours. Individuals are likely to be motivated not to engage in risky behaviours and it may be helpful to engage them in dialogue about whether medication could have a role in supporting them behaving in their preferred ways. Engagement is a key factor in managing risk and a recovery approach, which involves dialogue, negotiation and respect for the individual's beliefs is likely to enhance engagement. If a person feels that the goal of a service is primarily to give them medication that they don't like or want, they are likely to disengage. There may be situations when mental health workers believe that medication is a key component in maintaining safety and the person who is prescribed the medication does not agree. Under these circumstances, mental health workers have a responsibility to ensure that the person is compliant with their medication. This will be discussed in more detail below.

3. Understanding the patient's knowledge, beliefs and concerns about medicines, including side effects, dependency and withdrawal and how to fit the medication into their daily routine, being aware that some people may wish to minimise the amount of medication they take and explore non-pharmacological alternatives.

A recovery approach would seek to address concerns about adverse effects of medication by giving the person the opportunity to actively self-monitor and self-manage side effects, with an agreement about how unmanageable difficulties would be addressed. Mental health workers should also recognise that taking medication is likely to have significant personal meaning for people and may contribute to a sense of identity that is associated with illness or disability. There may also be stigma associated with using medication for mental health reasons and mental health workers should explore these issues with the person. People should also be informed about and given opportunities to try other options, either as an alternative to, or in combination with medication, including psychological and complementary therapies and self-help and self-management strategies.

There are a variety of tools available to support people in being responsible for managing their own medication, such as dosette boxes and reminder systems. Workers should discuss with people whether they might find any of these strategies helpful or support them in developing their own systems for fitting their medication into their lives. This could also include thinking with people about the timing of medication and whether they wish to involve any of their supporters in helping them to manage their medication.

4. Providing people with accessible and individualised information about their condition and medication, as well as directing them to other sources of information, so that they can be involved in making informed decisions about medicines.

There has been a tendency for prescribers to withhold information about possible adverse effects of medication but within an equal partnership it is important that mental health workers are honest about how medication is likely to impact on a person. There are also many possible sources of

information about medication, from the BNF to the personal experiences of other people who have used the same medication, all of which are subject to biases and limitations. While large randomised control trials are considered to be the gold standard in producing evidence based prescribing guidelines, the outcomes or the likelihood of publication may be influenced by funding sources, such as pharmaceutical companies, and say little about the experience of individuals or the longer term impact of medications. Conversely, personal accounts will be representative only of one individual's experience and be influenced by their personal values, priorities and lifestyle. Mental health workers should attempt to help people who use services to be aware of the range of sources of information about their difficulties and the medication they are being offered and to evaluate these. While this may create uncertainty, it will enable the person using medication to be an active participant in their recovery process.

### **Support for personal meanings**

Unlike many other conditions for which medicines are used, considerable controversy exists about the mode of action of psychiatric medication, whether it specifically treats an underlying imbalance in brain chemistry or operates through a more generalised sedating or stimulant effect. These hypotheses relate to wider unresolved debates about the causes of mental distress or disorder and the relative role of biological, psychological and social factors. A recovery approach does not endorse any particular framework for understanding and responding to distress but rather recognises the importance of an individual finding a coherent account of their difficulties that is personally meaningful, acceptable and useful to them. In discussing the possible role of medication for an individual, mental health workers should attempt to communicate that there are multiple ways of understanding the person's experiences and attend to the existing framework of belief about the nature of the problem that the person is likely to bring. While it is important to respect a person's existing understanding, it may also be helpful to them to discuss whether this way of understanding their experiences creates any difficulties for them and to offer them the opportunity to discuss this in more depth.

While an individual may not prefer a biomedical explanation of their difficulties or experiences, they may still find medication useful in achieving their recovery goals. Discussion of medication can focus on the likely effects and whether the individual would find these helpful. People may find that medication helps them to feel less distressed or overwhelmed irrespective of the cause of their difficulties. When people choose to use medication in this way they should also be offered the opportunity to talk about how they understand the cause of their difficulties and to explore strategies for addressing this.

### **Support networks and peer support**

People should be encouraged to involve their existing support networks in helping them make decisions about medication. People in caring and supporting roles are likely to have questions and notice changes that the person using medication may wish to take into consideration and can

encourage the person to bring up these concerns with mental health workers. People can also be encouraged to make use of peer support. Much informal knowledge sharing already takes place amongst people who take medication but this could be developed into more formal provision. People may be willing to add their name to a directory of people who have taken certain medications that people wanting to try those medications could access, or visits or group meetings could be held on in-patient wards and at community facilities. People can also be directed to existing peer support organisations both in their local area and online. As online communities vary in the nature of the support they provide and their stance on people's difficulties, workers should support people in evaluating what is being offered in the same way they would other sources of information.

Discussing medication can be seen as the preserve of medical staff. Pharmacists can be an invaluable source of information about medication and people should be offered the opportunity to access a pharmacist. Furthermore, workers of all disciplines and grades can support people in thinking about the possible role of medication in their recovery, finding out more about medication and possible alternatives and supporting them in being an equal participant in the prescribing process. Workers will also have their own experiences of taking medication, both for mental health reasons and other long-term health conditions and of using psychoactive substances to alter their mood and behaviour. They may be able to share these experiences in ways that inform and validate the person's decision making process in relation to medication.

### **Managing crisis and compulsory treatment**

At times when people are experiencing instability or crisis, it will be more difficult for them to participate in the prescribing process, especially as they may lack capacity. However, it is still important to try and follow a recovery orientated process as far as possible and to attempt to build capacity through engaging them in discussion about how they understand their difficulties and what might help, giving them information about the available options and exploring the risks and benefits. People may still be able to make choices, albeit from a more limited range of options. Capacity can fluctuate and may be present in relation to some decisions and not others, so it needs to be carefully assessed. As well as resisting decisions that appear to be in their best interests, people may appear to be consenting when they have not fully understood their situation.

Preparing for the possibility of a crisis, when someone may not be able to make decisions for themselves is important. Mental health workers should be honest about their limitations in relation to respecting someone's wishes and where possible responses should be negotiated and agreed in advance. People should be encouraged to complete crisis plans or advance directives so that their preferences can continue to inform the treatment they receive. People should also be encouraged to identify supporters who may be able to advocate for them and have useful historical knowledge of how treatments have affected them so that they can be involved in decision making.

There may be times when compulsory treatment is judged necessary to maintain the safety of a person or those around them. Unsafe situations can be thought of as being incompatible with personal recovery and mental health workers ultimately have a responsibility to maintain safety. Under these circumstances, workers should be honest and open with the person about their concerns and try to engage the person in a dialogue about how these concerns could be addressed. This should include a discussion about why other possible strategies for managing the concerns are not thought to be sufficient and how it can be demonstrated that the concerns are resolved and compulsory treatment is no longer necessary. Although it may not be possible to respect the person's wishes in relation to medication, the person should continue to be treated with respect. They should therefore continue to be offered information about the treatment that they will receive and be given the opportunity to raise their concerns and discuss possible ways that these could be addressed. They should be given as much choice as possible within the constraints of the situation: this could include choosing between possible medications and when, where and how they would like the medication administered. They should also be offered other treatments or activities which could support them in maintaining the safety of themselves or others. The person should be given the opportunity to express their feelings about receiving compulsory treatment and to explore their perspective on the situation. The need for compulsory treatment should be reviewed frequently and withdrawn as soon as possible.

Times of crisis and compulsory treatment should be treating as learning experiences and after they have resolved there should be an opportunity to reflect on how things could have been handled differently. Mental health workers should acknowledge the person's feelings about any actions that were taken against their wishes and a plan developed to prevent similar situations in future. The NICE guideline on schizophrenia recommends that people should be given the opportunity to record their own account of rapid tranquilisation in their notes and this approach could be extended to other forms of compulsory treatment.

### **Consultation with people who take medication, supporters of people who take medication and mental health workers**

#### **Method**

To carry out the wider consultation, a voluntary research assistant was recruited through the Clinical Psychology Department's graduate volunteer scheme. The use of an independent researcher was intended to enable people to respond honestly about their experiences of being prescribed medication.

It was decided to offer people a variety of response formats so that they could choose the one that was most comfortable and convenient for them. A questionnaire was developed which could be used as the basis of an individual interview, a group discussion or completed and returned anonymously to the researcher. The structure and content of the questionnaire was initially devised by the project group, then revised following

feedback from representatives of local service user groups. Different versions of the questionnaire were produced for people who take medication, their supporters and mental health workers (see Appendices 2, 3 and 4)

The project was publicised through service user and carer involvement workers, nursing staff at Russell Clinic and Langdon Hospital, posters in the waiting rooms at Wonford House and the Exeter Clinical Psychology Department, a stand at an internal conference on recovery, an item in the Devon Partnership Trust online news and an e-mail to the DPT staff distribution list. People were offered the opportunity to participate in an interview, express an interest in taking part in a group discussion or to receive a copy of the questionnaire and return it either by e-mail or freepost to the researcher. People who use services and carers were paid £5.73 per hour and any travelling expenses for participating in an interview or focus group. A copy of the consent form that was given to all participants can be found in Appendix 5.

Twenty-six people who were currently taking medication for mental health reasons and who had received a service from Devon Partnership Trust adult mental health or forensic services responded. All opted to be interviewed either in their own homes, the Exeter Clinical Psychology Department or at a local base for mental health services. Interviews lasted between one and two hours. A total of nine carers responded: two returned questionnaires by e-mail, three participated in individual interviews and four attended a two hour group discussion session. Seventeen mental health workers responded by returning questionnaires either by e-mail or through the internal post. Two expressed an interest in also attending a group discussion but there was not enough interest from other workers to make this possible. The distribution of participants across the network areas is shown in Table 1.

Table 1. Network areas with which participants had had contact *at any time*

	Access & Well Being	Recovery & Independent Living	Urgent & In-patient	Forensic	Not specified
Takes medication	4	13	14	8	2
Supporter	3	3	5	0	4
Worker	2	4	2	3	10

The ratings given by each group to the rating scale at the beginning of the questionnaire were compared using a Kruskal Wallis one-way ANOVA by ranks. The qualitative data was analysed using thematic analysis (Braun & Clarke, 2006). This involved initially coding the data and then searching for themes or patterns that best represented the views within the whole data set. Illustrative quotes were extracted to support and give validity to these themes identified. The aim was to discover themes that reflected the meanings evident in the data set as a whole.

## Results

### ***Quantitative data***

The first item on the questionnaire asked participants to rate on a scale of 1 to 10 how important generally they thought medication was to people's recovery, where 1 was not at all important and 10 was extremely important. The mean scores for each group are shown in Table 2.

Table 2. Mean ratings (and standard deviations) of the overall importance of medication for recovery

	Takes medication (N=26)	Supporter (N=9)	Worker (N=17)
Mean (s.d.)	6.58 (2.48)	6.44 (2.13)	6.82 (2.42)

The Kruskal-Wallis test found no significant differences between the groups ( $H(2) = 1.99, p > 0.05$ ).

### ***Qualitative data***

There was considerable consistency in the themes that emerged from the responses of people who had taken medication, their supporters and mental health workers. A fuller description of the themes, and supporting quotes can be found in Appendix 6.

#### Role of medication

In all three groups, people generally described the role of medication as a short-term strategy to manage crisis, create stability or to get difficulties under control. This could then be a foundation for a recovery process which might involve other strategies. There were considerable differences between people in their experience of using medication and the need to recognise differences between individuals emerged as a theme.

#### Limitations of medication

Medication was also identified as undermining or hindering recovery, mainly due to side effects. Many people said that medication should not be the only available strategy and most people felt that it was important to explore alternatives, especially talking therapies.

#### Medicines management processes

People who take medication and their supporters reported a considerable amount of negative experiences in communicating with mental health workers about medication. People felt that their concerns were not taken seriously and that their experiences were dismissed or pathologised. All groups emphasised the need for a collaborative relationship between people taking medication and their workers. Key components of this relationship were listening, giving information about medication and side effects, negotiating and offering choice and monitoring the effects of medication.

### Managing crisis

All groups identified the value of a crisis plan to ensure that a person's wishes were respected at times when they might not be able to safely make choices for themselves. However, it was identified that such plans were not always respected even when they were in place. Other safeguards identified were involving advocates or informal supporters in decisions about medication at these times. Workers also emphasised the importance of continuing to try and engage the person taking medication in decisions even when they were having difficulties.

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## Appendix 1

### Membership of the Project Steering Group

Elina Baker (project lead)	Clinical psychologist (Exeter Rehabilitation Hub)
Louise Bovington	Graduate Volunteer (Exeter Dept of Clinical Psychology)
Tina Campbell	Associate Director of Medicines Management
Jason Fee	Consultant Forensic Psychiatrist (Butler Clinic)
Elaine Hewis	Independent mental health consultant with lived experience of taking medication for mental health reasons
Danny Lewis	Supporter of person taking medication for mental health reasons
Lesley Mahoney	Staff nurse (Russell Clinic)
<b>Consultant to project group</b> Glenn Roberts	Consultant Psychiatrist (Exeter Rehabilitation Hub)