

# Involving service users

*This booklet introduces the role of service users in commissioning and providing services for people who have a serious mental illness. Follow the toolkit to explore themes that have been identified by people with lived experience as important issues.*

Listening to the service users and carers – often referred to as ‘service user voices’ or ‘experts by experience’ – is critical in understanding the causes of premature death in people living with serious mental illness (SMI), including risk factors and social determinants. Their perspectives must be incorporated in the design, delivery and evaluation of recommended activities in order to improve the opportunities for closing the mortality gap for this group of people.

There is a contradiction in the aspiration to support individuals to self-manage their physical health in a system that is often described as prescriptive and focused on risk, symptoms and treatment. The need for policy makers, commissioners, providers and service users to continually work together to address these issues is as relevant to physical health outcomes as it is to mental health. Mental and physical health should not be treated separately. When an individual’s mental health suffers, so does their physical health and vice versa.

Involving service users and people who have experienced mental health and physical health concerns will help achieve healthcare that can effectively respond to the needs of people living with severe mental illness.

## The medical model

When treating someone with serious mental illness, thinking of poor physical health outcomes as a medical problem with a medical solution fails to recognise the complexity of issues. There is a need to move from a model that is focused on risk, symptoms and treatment, to one that considers:

- The wider context of the person’s current situation (housing, employment, etc.) on their health and wellbeing.
- The wider exploration of treatment options that are broader than psychiatric medication.
- Risk within the individual’s context – through developing shared risk-management plans.

This would contribute to a wider, more holistic and alternative approach. It would be personalised to an individual’s situation and meet their diverse needs. It would be able to address their physical health issues that can negatively impact on health and wellbeing.

### Recommended actions to take

- Encourage innovation in ways to promote healthy lifestyles that are less reliant on medical interventions, delivered beyond conventional health settings, and optimise community assets – for example, service user-led resources, voluntary sector and faith-led organisations
- Ensure that care planning is personalised and reflects the service user’s wider needs, including social care and mental health needs, and applying social prescribing.

### Tools to help you

- [The Bradford Mental Health Physical Review Template](#). A specially designed screen developed for the SystemOne, EMIS Web and Rio IT systems that collects all the physical health data required for each service user in one place and links to relevant guidance on treatment and intervention. The template now includes all the data recommended by the Lester tool but has a few additional sections designed to meet the specific requirements of Bradford District Care Foundation Trust.

## Providing essential information

Too little information is currently given to service users – for example, information about using psychiatric medications and their side effects, self-management and other supporting resources. Giving people more information they can easily understand would support them to make

informed decisions regarding their mental and physical health care and lead to better health outcomes.

### Recommended actions to take

- Involve service users and carers in the design and delivery of systems for the annual health check, including peer support to enhance attendance and benefits from the assessment.
- Use peer support roles to encourage service users to attend their appointments.
- Use peer mentoring to support people to take up opportunities to improve their physical health.

### Tools to help you

- [Rethink: 20 years too soon report](#). Rethink's report on physical health experiences of people who use mental health services and their carers and families. It sets out challenges and recommendations.

## Improving access to services

Barriers to good physical health include lack of access to services or activities that people living with serious mental ill health find useful or personally relevant.

### Recommended actions to take

- Provide reasonable adjustments to support access to services and encourage attendance, such as longer and more flexible appointment times.

### Tools to help you

- [Developing and putting in place 'reasonable adjustments': Working Together in Support](#). The Royal College of Psychiatrists have examples of where general practice can make reasonable adjustments for people with an SMI.
- [Discrimination and mental health– Rethink Mental Illness](#)
- [Five Year Forward View Mental Health Taskforce](#) sets out key themes that emerged from the public engagement findings: prevention, access and quality.

- These key themes are important target areas to help achieve optimal mental and physical health outcomes for people living with severe mental illness. They are consistent with the key principles set out in the [Five Year Forward View for Mental Health](#).
- [Parity in Progress? – Mind](#). The All Party Parliamentary Group on Mental Health conducted an inquiry into parity of esteem for mental health, and one of the areas they felt that there was greatest disparity between mental health and physical is in the SMI mortality gap.
- [Mental Health Foundation: Crossing the Boundaries. Final Inquiry Report](#). The Mental Health Foundation’s Inquiry into integrated health care for people with mental health problems provides good practice examples.

## Co-production: involvement and influence

Involving people with serious mental ill health and their family and carers in the design and commissioning of physical healthcare provision empowers individuals. Their involvement can help develop relevant and useful resources and improve service access and associated health outcomes. This can mean a change in service culture and can have pronounced benefits for both service users and staff.

### Recommended actions to take

Support routine involvement of service users and carers, ideally through a co-production approach, in:

- Developing, delivering and evaluating a strategy with planned initiatives to address the SMI mortality gap.
- Service specifications, delivery and evaluations.
- Identifying processes, outcomes and user-led measures that are meaningful to service users to evaluate services. For example, taking into account increased confidence and social contacts, as well as measures of physical health indicators, such as weight or glucose control.
- Training and education, user-led training, development of physical health self-management tools, information packs, clinic invitations or clinical environment design

## Tools to help you

- [Co-production in Mental Health: a literature review. New Economics Foundation 2013.](#) Mind commissioned the New Economics Foundation to carry out a review of existing evidence regarding co-production. It examines when, why, and how co-production has been used in mental health and what impact it has had on people's lives and their recovery.
- [Co-production in mental health commissioning.](#) Rethink Mental Illness has a range of resources and tools based on their programme and Mental Health in Co-production evaluation Project
- [Practical Guide: Progressing transformative co-production in mental health.](#) The National Development Team for Inclusion have developed a suite of resources for transformative co-production, aimed at different audiences, including the practical guide
- [4Pi National Involvement Standards.](#) Developed and produced by people with lived experience, NSUN established some basic principles to encourage people to think of involvement in terms of principles, purpose, presence, process and impact (4Pi)
- [Ladder of co-production](#) Created by members of the [National Co-production Advisory Group](#), this guide describes a series of steps towards full co-production in health and social care. It supports greater understanding of the various pre-steps such as 'access', 'inclusion' and 'consultation'.

## Care planning and self-management

Mental health experiences, such as low mood, low self-esteem and symptoms of psychosis, can make it difficult for people to look after their physical health. Empowering service users to self-manage their physical health is vital. Often service users are not provided with the information and guidance they need to manage their physical health. Community settings are essential in providing advice, support and activities to improve self-management.

## Recommended actions to take

- Deliver interventions to support self-management of physical health and wellbeing that emphasise the positive roles peer support (accessed through service user-led and voluntary organisations) and supportive family and friends can play.

- Support prescribing guidelines and side-effect management with alternative strategies, such as social prescribing, peer and community support.
- Ensure informed and shared decision making and the involvement of family and unpaid carers in care planning.

## Tools to help you

- [Wellbeing & Physical Health](#). Rethink have produced some guidance for patients on looking after their wellbeing and physical health.
- [Mental health problems: self-care resource](#). Self-care tips for people living with a mental health condition, produced by Mind.
- [Physical activity, sport and exercise resource](#). Overview of the health benefits of being physically active, produced by Mind.

## Creating supportive environments

Some service users have negative experiences of mental health and physical health services. It affects their trust and creates reluctance to access services

Service users experiencing mental health difficulties or distress often encounter negative attitudes or a lack of respect from staff (or both). This is more common when they belong to marginalised communities. In order to support an individual in taking more control of their mental and physical health and wellbeing, they need to be treated with respect and compassion. Empathy, compassion, good communication, strengths-based approaches that explore people's inner resources to manage their condition, curiosity about the individual's values and core beliefs, and care about someone's whole life are important for supporting a positive approach to self-management.

*Fundamentally, consistency, trust, being knowledgeable and kindness are important for both physical and mental healthcare, but particularly for people with mental health problems accessing physical healthcare. One unpleasant encounter, even with a receptionist, and I may not come back as the psychological effort and stress to return will be considerable. – Service user feedback, Healthy Lives Project Report*

## Recommended actions to take

- Make adjustments to screening tools and clinical environments to deliver positive, creative and strengths-based approaches to physical health care – rather than only highlighting risks in physical health management.
- Provide mental health awareness training for all staff to ensure a positive, welcoming and warm environment is created. It is important that the first point of contact, often reception staff, is trained to ensure a positive first experience for the individual.

## Tools to support you

- [Healthy Lives Project report](#): We commissioned this report from the National Survivor User Network (NSUN). It offers insight into the physical healthcare experiences of people with serious mental illness.

### Meeting diverse needs

Marginalised groups, including racialised communities remain at the highest risk of poor physical health. Action must be taken to ensure this is addressed. Local commissioners and providers need to work closely with individuals and local communities – always including racialised communities – to find alternative approaches to engage and equalise opportunities and outcomes.

## Recommended actions to take

- Recognise the diversity of local communities and make resources available that reflect this diversity.
- Work with marginalised communities to identify the best use of non-health-based community supports. For example, service user or voluntary sector organisation-led initiatives.
- Deliver interventions using a personalised approach that optimises social prescribing and community resources.
- Build relationships with trusted community organisations where people from marginalised communities feel safe to access support

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