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Service User, Family Member and Care Engagement in Mental Health Services: A Review of the Literature

May 2018
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Executive summary
Executive summary

This evidence review was commissioned in October 2016 by the Mental Health Engagement Office to support the work currently being undertaken to develop structures, systems and mechanisms for service user, family member and carer engagement. Its purpose is to extract and highlight key messages from the literature regarding what has been shown to be effective in the engagement of service users in mental health services, as well as the challenges and barriers identified.

In 2014 the HSE Mental Health Division (MHD) established a reference group of service users, family members and carers and HSE staff to develop recommendations for the structures and mechanisms for service user, family member and carer engagement. The recommendations of this reference group were published in 2016’s Partnership for Change report. The MHD Report on the Listening Meetings was published the same year. The listening meetings represented one of the largest consultations ever undertaken by the MHD with service users, family members and carers. The report focused on what was being done well by the MHD and what areas needed improvement. The views of 1,100 people were reflected in the report. These reports sit alongside a range of ongoing activities which, when taken together, are beginning to generate an environment open to the embedding of structures for engagement with service users, their families and carers. The findings of this review will support and inform the implementation of the Reference Group recommendations through establishing what has shown to be effective and what has been shown to be challenging and reflect the MHD priority to ensure that the views of service users, family members and carers are central to the design and delivery of mental health services.

Service user, family member and carer engagement in mental health services is promoted in national and international policies, strategies and initiatives. It is widely recognised that there are many potential benefits to service users, carers, service providers, staff and wider society. However, implementation of these approaches appears to be challenging and the evidence for their effectiveness has been mixed.

A range of different terms for ‘service user’ and ‘engagement’ are used in the literature. Each term has its own history and connotations, yet they refer to broadly similar things. This diversity and nuance makes it harder to draw clear messages from the literature. This review uses the terms adopted by the Mental Health Engagement Office for the sake of clarity and consistency.

A range of issues should be attended to regarding service user engagement in any setting; some of these challenges are more pronounced in the context of mental health services and require attention. The following issues have been identified:

- Power imbalances
- Attitudes of staff
- Tokenism
- The changing roles of service users
- Individual-level influences
- Organisational influences
- Diversity and representation
- Lack of action
- The right to opt out.

There are many different models of service user engagement. Some models imply that there is a hierarchy of meaningful engagement. However, it is important to note that engagement can be meaningful when users have agency and the ability to shape the methods used. These may change over time and so flexibility is required on the part of service providers.

Service users can be engaged at different levels. They can be engaged in their own care planning and management (termed the individual level), in local service delivery and development (termed the community level, or the local and area levels), in the running of services or organisations (the operational level), and in policy development and implementation (the national and strategic levels). This review focuses on engagement at the operational and community levels and the strategic and national levels, rather than the engagement/involvement of service users in their own care. This review considers involvement in local service management and service planning, as well as...
service user involvement in policy development, monitoring, commissioning and governing, reflecting the work of the MHD at the local and area levels and the national level.

A range of potential mechanisms for engagement exist. The mechanism adopted should reflect the purpose of the engagement effort and be influenced by service users. Service users want to be engaged, but not necessarily extensively or on every issue. Instead, they want to be engaged appropriately and to have a real influence. Different mechanisms of engagement are required depending on the purpose.

This review of the literature, guidelines and recommendations suggests several consistent messages for service providers and service users, family members and carers to ensure that engagement is meaningful and effective.

1. Understanding the value and purpose of service user engagement
   □ Service providers must be committed to engagement
   □ Service providers must understand why the service they provide should involve service users in the design, delivery and evaluation of their services
   □ Service providers must have a shared understanding of the role of service users, in engagement efforts and in the service as a whole
   □ Service providers must have a clear understanding of their own role/roles in service user engagement activities
   □ Service users should know why they are being involved and how their participation is intended to affect service design, delivery and implementation
   □ Service users should have access to clear information to facilitate informed understanding.

2. Who should be engaged?
   □ All service users should be eligible to be involved in service user engagement activities
   □ Special efforts should be made to involve a representative group of service users
   □ Participation should be voluntary
   □ Service providers must recognise that engagement can pose risks to service users, and they should take steps to minimise these risks
   □ Staff with the right skills for engagement should be involved.

3. How should engagement happen?
   □ Services should adopt a rigorous approach when identifying the purpose, aims and objectives of engagement activities
   □ Service user engagement opportunities should take a variety of forms
   □ The process of involvement is as important as content
   □ Service users can be involved in engaging other service users
   □ Service users will need support to engage optimally
   □ Service providers need to be supported to engage meaningfully
   □ Ongoing feedback to service users can help to build and maintain their motivation for engagement, trust and confidence
   □ Ongoing monitoring should incorporate measures identified and endorsed by service users.

4. Is it making a difference?
   □ The impact of service user engagement efforts must be evaluated, despite the challenges this presents
   □ Service users and service providers should receive feedback on engagement efforts
   □ The success of service user engagement should be celebrated with service users and staff.

This review should not be seen as a final word on what works regarding service user engagement. Rather, it should be seen as a contribution to a conversation with service users, family members and carers, service providers and other stakeholders regarding what could work and how it could work.
1. Introduction
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Background and purpose of the evidence review

This evidence review was commissioned in October 2016 by the Mental Health Engagement Office to support the work currently being undertaken to develop structures, systems and mechanisms for service user, family member and carer engagement. Its purpose is to extract and highlight key messages available from the literature on what has been shown to be effective in engaging service users in the mental health services, as well as challenges and barriers.

The evidence review focuses on service user engagement with a view to designing, planning, improving and evaluating services, rather than the involvement of service users in their own care planning. The review focuses on service user engagement in adult mental health services.

The MHD established a Reference Group in 2014 to make recommendations on the structures and mechanism for service user, family member and carer engagement. The membership comprised nine service users and four family and carer representatives. The group completed their work in between August 2014 and July 2015, making recommendations to promote widespread and regular engagement and consultation with service users, family members and carers at local and national level.

The five main areas of the Reference Group recommendations are:

1. Establishing the role and function of the Head of Mental Health Engagement as a member of the National MHD Management Team
2. Establishing the role and function of the nine Area Leads of Mental Health Engagement as members of the Area Mental Health Management Teams
3. Establishing structures and mechanisms for feedback and consultation through Local and Area Fora
4. Providing capacity building required to support the engagement mechanisms and roles.
5. Defining the role of the Office of the Head of Mental Health Engagement

These recommendations now form the ongoing framework for the work of the Head of Mental Health Engagement and office staff. Former members of the Reference Group are continuing to assist the MHD on matters relating to the implementation of the recommendations on an individual basis pending the establishment of the new engagement structures. A Project Implementation Steering Group was established in 2015. In April 2016, the Report on the Listening Meetings was published. This report brought together the findings of several events held to hear the experiences of service users, families and carers engaged with the mental health services.

These reports, along with a range of other activities, are beginning to generate an environment open to the embedding of structures for engagement with service users, their families and carers. The findings of this review will support and inform the implementation of the Reference Group recommendations through establishing what has shown to be effective and what challenges exist.

Service User Engagement in Mental Health Services

Over recent decades, governments and services around the world, particularly in Europe, North America, Australia and New Zealand, have increasingly emphasised service user engagement. Policy makers and service providers are focused on the role of service users in the planning, delivery and evaluation of mental health services. At the international level, user engagement has been promoted by the World Health Organisation (WHO). Several countries have also developed legislation to strengthen the influence of service users and to give them greater control over the services they receive.

These developments follow a general trend in Western and developing societies whereby citizens expect a greater say in how the services they use are designed and delivered. Contemporary health policies see users and carers as important stakeholders in service delivery and must therefore be treated as participants rather than recipients of care. Involving service users and carers in the planning and delivery of services has been shown to have positive effects on both service outcomes and outcomes for individual service users as well as empowering service users, promoting resilience and providing opportunities for peer support and mentoring. It can also have positive effects on

1 NSUN (2015); Commonwealth of Australia (2009); HM Government (2011); Daremo and Haglund (2008); Goodwin and Happell (2008).
decision-making processes, relationships with staff and access to services. However, the evidence also suggests that implementing service user engagement in practice is not easy.

**International policy and practice context**

Service user engagement, participation and empowerment has been promoted at the international level by the World Health Organisation in the European Mental Health Action Plan (2013–2020) and the Mental Health Declaration for Europe 2005.

**WHO European Mental Health Action Plan 2013–2020**

The WHO European Mental Health Action Plan focuses on seven interlinked objectives and proposes effective actions to strengthen mental health and well-being. Objective 4 of this action plan states that the relationship between the mental health care sector and patients is the key to the effective delivery of mental health services. One of the proposed actions for Member States is to allow service users to share in decisions about the prioritisation, development and implementation of innovative and effective treatments, at both system and individual levels.

**Mental Health Declaration for Europe 2005**

The 2005 Mental Health Declaration for Europe, signed by member states of WHO, sets as a priority to recognise the expertise and knowledge of service users and carers as an important basis for planning and developing services.

**The United Kingdom**

In the UK, the National Survivor User Network (NSUN) is a user-led charity that has developed the 4Pi National Involvement Standards. The aim of the 4Pi standards is to provide a framework for establishing good practice in the involvement of service users and carers in mental health care, service delivery and policy, and for monitoring and assessing that involvement. It centres on four principles: purpose, presence, process and impact. The framework is accompanied by a compendium of Service User Involvement in Health and Social Care Policy and Legislation. This compendium provides an overview of service user involvement in health and social care policy and legislation in the UK from the NHS and Community Care Act of 1990 up to the 2014 Care Act. The document can be accessed [http://www.nsun.org.uk/assets/downloadableFiles/4Pi-SERVIC EURUSERINVOLVEMENTINHEALTHANDSOCIALCAREPOLICYv62.pdf](http://www.nsun.org.uk/assets/downloadableFiles/4Pi-SERVICEURUSERINVOLVEMENTINHEALTHANDSOCIALCAREPOLICYv62.pdf).

The charity Rethink Mental Illness delivered the Mental Health in Co-production (MiC) project, funded by the Department of Health’s Health and Social Care Volunteering Fund for three years up to 2015. The charity worked in partnership on pilot projects in four London boroughs. The objective of the project was to create an evidence-based best practice model for using co-production in the commissioning of mental health services. The project trained ‘Champions’ (often service users) and commissioners to enable them to work effectively together to co-design services. The community Champions used their own networks of local volunteers with personal experience of mental health problems to understand the challenges facing the local community and the assets within it.

**Nordic Countries**

The Nordic Research Academy for Mental Health conducted an overview of mental health policy in Nordic countries (excluding Iceland) in 2011. The report identified common mental health policy goals in the participating Nordic countries, including the ‘empowerment of service users’. Other common goals included universal access to decentralised care, reduction of hospital-based and coercive care, and investment in prevention. Each goal has been implemented differently in each country reflecting differences in history, legislation, healthcare governance and resource allocation.

**Australia**

In Australia, the Fourth National Mental Health Plan: An Agenda for Collaborative Government Action in Mental Health (2009–2014) includes among its national actions the commitment to ‘Adopt a recovery oriented culture within mental health services, underpinned by appropriate values and service models’ and the associated aim to expand opportunities for enhanced participation of consumers and carers. In 2014, the National Review of Mental Health Programmes and Services recognised that “people with lived experience, their families, carers and supporters should be engaged in formal and informal ways which enable their involvement in decision-making at all levels”. The Fifth National Mental Health Plan is currently out for consultation. The draft version outlines that there is “increased recognition of the need to involve consumers and carers in decisions”.

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3 Crawford et al. (2002); Simpson et al (2002); Pitt et al (2013).


5 Department of Health and Ageing (2009).

Co-production is listed as one of the core values underpinning the Fifth National Mental Health Plan, with the document recognising that:

“Consumers and carers have vital contributions, and should be partners in planning and decision-making. Consumers and carers should be at the centre of, and enabled to take an active role in shaping, the way in which services are planned, delivered and evaluated.”

The National Mental Health Commission produces Report Cards, identifying and reporting on several areas that are important to consumers’ ability to lead a contributing life.

A new national mental health consumer organisation ‘the National Mental Health Consumer Organisation (NMHCO)’, sponsored by the Mental Health Council of Australia (MHCA), has been proposed. The Mental Health Council of Australia (MHCA) is the primary, national non-government organisation representing and promoting the interests of the Australian mental health sector.

Membership includes national organisations representing consumers, carers, special needs groups, clinical service providers, public and private mental health service providers, researchers, and state/territory mental health peak bodies. The National Mental Health Consumer Organisation (NMHCO) Establishment Project worked towards establishing a new national peak organisation for mental health consumers. The Consumer Reference Group (CRG) and Mental Health Australia worked in partnership to develop the foundations with a focus on a sustainable organisation, good governance, governed by and for, people with lived experience of mental illness and mental health issues. The Project commenced in 2012 and finished in 2015. However, funding was not secured to launch the organisation. A range of resources were developed during the project, including:

- A draft Guide to the Organisation and its Constitution
- A draft Constitution
- A draft Corporate Governance Manual

These resources are available on the website of the Mental Health Council of Australia. The draft guide to the organisation contains the stipulation that the Board includes a maximum of nine Directors, six of whom must be people with lived experience of mental health issues or mental illness.

Also in Australia, the National Mental Health Consumer and Carer Forum (NMHCCF), established in 2002, represents the combined national voice for mental health consumers and carers participating in the development of Australian mental health sector and its services. The NMHCCF gives mental health consumers and carers the opportunity to meet, form partnerships and be involved in the development and implementation of mental health policy reform.

The NMHCCF meets four times a year either face to face or by teleconference, it progresses projects identified as priority areas by NMHCCF members, provides advice on specific national mental health initiatives and makes submissions on relevant national issues. It advocates for mental health consumer and carer representation at all levels, from policy development to service delivery.

Membership comprises one representative mental health consumer and carer from each Australian state and territory and representatives from major population groups and a number of national health consumer and carer organisations.

**New Zealand**

In New Zealand the first action area of the recent 2016 health strategy is entitled ‘People Powered’. This theme is relevant to the current review as it refers, among other things, to:

- Enabling individuals to make choices about the care or support they receive
- Understanding people’s needs and preferences and partnering with them to design services to meet these


9 Minister of Health (2016).
Communicating well and supporting people’s navigation of the system, including through the use of accessible technology such as mobile phones and the internet.

Another theme, the ‘One System’ approach, is described as requiring a united team of health professionals, carers and volunteers, suppliers of goods and services, researchers and those working in related areas such as housing, education and employment. To support this approach, the Ministry of Health plans to facilitate forums for the whole system every year to discuss government priorities, share international and New Zealand best practices and build leadership. Feedback from the forums will be used to inform system priorities. The forums are intended to contribute to a culture of trust and partnership, within the health sector and across other sectors, with consumers and other actors.

Canada

The Canadian Mental Health Association–Montreal Branch (CMHA–Montreal) is a community organisation dedicated to mental health promotion and prevention of mental illness. It has established an initiative called the Carrefour Communautaire-Institutionnel-Usagers (Connecting Community organisations-Institutions-Users, or, the CCIU). The CCIU is mandated to promote the participation of users and carers in the planning, organisation and evaluation of mental health services in order to improve services and coordinate care by providing a forum where ideas can be exchanged and freely expressed. The main goals of the CCIU involve:

1. Forging connections and sharing viewpoints among the stakeholders in order to develop better knowledge and a better understanding of lived experience, in particular that of users and carers
2. Sharing information regarding the settings and organisations that the participants are involved in
3. Promoting users’ involvement in the organisation of services and better services by considering the advantages of integrated care (in particular the notion of normative and horizontal integration).

Initially, the CCI (as it was first called) came about in 1998 to make connections between mental health workers from community organisations and institutional settings. Over time the importance of involving users and carers in the dialogues was recognised. In 2009, the CCIU formalised the presence of all four types of stakeholders (community and institutional stakeholders, users, and carers). The CCIU enables these stakeholders to exchange ideas on various topics related to mental health at 7 meetings held throughout the year in locations outside of the work context (with between 15 and 20 participants per meeting). Participation is voluntary with an emphasis on achieving a representative group of all stakeholders with a minimum of 50% of users and carers is required. The CCIU has been evaluated through an internal survey and it has been systematically evaluated based on a logic analysis of its components to understand of how it operates.

The logic analysis indicated that, by forging connections between individuals who voluntarily attended meetings, mutual trust gradually developed. The resulting openness to others led to better knowledge and understanding of individual and collective realities and a better shared understanding of certain core concepts including ‘recovery model of care’ and ‘integrated care’. This has led to changes in perceptions and attitudes. It has facilitated a gradual reduction in prejudice and encouraged personal introspection and shared values and philosophies among all participants. This, in turn, has led to support and enthusiasm for changes in practice. The CCIU is a relatively recent initiative (since 2009), and so concrete changes in practice cannot easily be demonstrated or evaluated. Nevertheless, several participants consulted for the logic analysis agreed that the CCIU had enabled them to progress towards changes in practice.

A number of key elements were noted as core to achieving the goals of the CCIU including the small number of participants, the proportion of service users and carers, the absence of hierarchical relations between participants, and direct contact between mental health workers, service users and carers. The logic analysis pointed to the need to maintain the following elements: clear group rules that promote mutual respect and encourage discussions beyond financial and power issues.

Leadership was also noted as an essential component in the achievement goals. The importance of holding meetings outside of regular work settings was emphasised for creating a forum for dialogue and free speech, supporting the emergence of shared meaning and fostering effective communication between the different stakeholders.

HSE Mental Health Division policy context

The MHD seeks to prioritise service user, family member and carer engagement. These structures and mechanisms for engagement are informed and influenced by service users, carers and family members.

10 Tremblay, Coulombe and Briand (2017).
Mental Health Division Operational Plans 2015 and 2016

The Mental Health Division Operational Plans for 2015 and 2016 set out the framework and actions that mental health services will put in place to ensure that service user and carer engagement is incorporated into decision making. The Mental Health Engagement Office leads and implements the development of structures, systems and mechanisms for service user, family member and carer engagement under the direction of the Head of Mental Health Engagement. As the role develops, the office will offer advice and support in relation to engagement and will support the development of capacity building for those involved. The Office also aims to develop knowledge and expertise in engagement, and to work with other stakeholders to promote service user, family member and carer engagement in all mental health services.

Work started in 2014 to ensure that the views of service users are central to the design and delivery of services. This was further developed in 2015 through completion of the Reference Group report and recommendations on mechanisms, including consultation and feedback mechanisms, for the participation of service users, families and carers in the decision-making processes of mental health services at local and national levels.


In August 2014, the Mental Health Division established a reference group to make recommendations on the structures and mechanisms for service user, family member and carer engagement. The primary task of the reference group is to propose mechanisms for promoting widespread and regular consultation with service users, family members and carers in relation to HSE mental health services at local and national level. Partnership for Change is the Report of the Mental Health Reference Group, making recommendations on structures and mechanisms for service user, family member and carer engagement.

Irish policy context

An increasing number of policies, strategies and plans in Ireland are highlighting service user engagement, participation and involvement.

HSE Corporate Plan 2015-2017

The HSE Corporate Plan states that it will enhance engagement with patients and service users, their families and carers and involve them in the design and delivery of services. The plan outlines commitments to listen with respect, kindness, consideration and empathy to patients, service users and carers when planning, delivering and making improvements services, in line with the values of care, compassion, trust and learning.

Healthy Ireland – A Framework for Improved Health and Wellbeing 2013 – 2025

A core aim in The Healthy Ireland framework is to strengthen participation in decision making for health and wellbeing at community level and increase levels of service user involvement in the health service, at local authority level and in other sectors.

National Strategy for Service User Involvement in the Irish Health Service 2008–2013

This strategy was developed to ensure a systematic and consistent approach to service user involvement across the health and social services. It builds upon existing practice in involving service users across the country. The strategy was a significant step forward in developing strong service user involvement in health in Ireland. It advocates that service users should be central to the design and delivery of health and personal social services. This strategy recognised that service user involvement would result in more appropriate services of a higher quality with increased service user compliance and satisfaction.


A Vision for Change details a comprehensive model of mental health service provision for Ireland. As a necessary step towards more equal and fair communication between all mental health participants, the report recommends that service users and carers should be included as active partners in the planning and delivery of mental health services. The report recognises that involving service users in mental health services goes beyond simply carrying out a consultation process.

Service users must be at the centre of decision making at an individual level in terms of the services available to them, through to the strategic development of local services and national policy.

The report recommended that a National Mental Health Service Directorate be established consisting of senior professional managers, senior clinicians and a service user. This Directorate should act as an advisory group and be closely linked with the management of the Primary and Continuing Community Care Division of the Health Service Executive. The report also called for service users
to be involved in implementing and evaluating the new mental health policy through involving service users at all management levels and functions, including resource allocation, from local health offices up to the proposed National Mental Health Service Directorate and the Mental Health Commission.

Other policy areas

Engagement, participation, and involvement are an increasingly common feature in a range of policy and service areas, and feature prominently in policies and strategies relating to children (e.g. the National Strategy on Children and Young People’s Participation in Decision Making, 2015, and the National Children’s Strategy, 2000).

Key concepts and terminology

Terminology is an important issue when it comes to service user engagement because it facilitates clarity regarding:

- Who is engaged
- Who is doing the ‘engaging’
- How they see themselves
- How they are seen in their roles in the engagement process
- The forms and depth of engagement
- Where and how engagement happens.

Service Users

Terms used to describe people who use services vary across the literature. The choice of terms can be controversial and can vary both within and between groups and locations, with terms such as ‘consumers’, ‘service users’, ‘patients’, ‘clients’ or ‘survivors’ being used.

The language used to describe service users is perhaps more varied in mental health than in any other sector of health and social care. The terms ‘service user’ (common in the UK and Europe), ‘consumer’ (in the US and elsewhere), ‘tangata whaiora’ (a New Zealand term denoting a person seeking well-being), ‘expert by experience’ and ‘survivor’ (originating in the Netherlands and the USA, common in the UK) are among the terms used in the literature.

Individuals with personal experience of mental illness differ with regard to how they prefer to be addressed. Service users are typically represented as patients and are defined in terms of their illness. Seeing service users instead as consumers, experts by experience, survivors, peers, or co-producers requires a shift in the perceived roles and responsibilities of people with mental health problems and has implications for their relationship to mental health services and mental health professionals.

Each of these terms has its own connotations and implications. For example, constructing service users as consumers implies they have a choice of services and can select their preferred option, although there may be a limited choice and a lack of means to procure them.

In Ireland, the National Strategy for Service User Involvement in the Irish Health Service (2008) defines service users as:

- People who use health and social care services as patients
- Carers, parents and guardians
- Organisations and communities that represent the interests of people who use health and social care services
- Members of the public and communities who are potential recipients of health promotion programmes and social care interventions.

The inclusion of carers under the definition of service users has significant implications for the development of service user involvement. The following definitions of carers are drawn from the final report of Australia’s Identifying the Carers project and illustrate a range of understandings and perspectives on what constitutes a carer:

- European Carers Charter (June 2007): Carers are non–professional people who take care of patients at home. Carers can be relatives of the sick person or other voluntaries. They usually give help or support to relatives or friends because of a long term physical or mental illness or disability.

11 Wallcraft et al. (2011).
12 Tait and Lester (2005).
14 Mueser, Glynn, Corrigan, and Baber (1996).
15 Pilgrim and Rorges (1999).
16 McLaughlin (2009).
Canadian Palliative Care Association, (1988): Carers are those closest to the patient in knowledge, care and affection. This includes the biological family, the family of acquisition (related by marriage/contract), the family of choice and friends (not related biologically by marriage/contract).

United Hospital Fund Families and Health Care Project, New York (2006): Family caregivers include relatives, partners, friends, or neighbours who provide essential assistance to an adult or child with chronic illness or disability or to a frail or cognitively impaired older person. Some of the ways in which the family may respond are emotional support, surrogate decision making, financial contributions, care management, and hands-on care. (Parents of well children or children without disabilities are not considered family caregivers in this sense.) Family caregivers may provide or manage all or some of the care, either part-time or full-time, and may or may not live with the care recipient.

Northern Territory, Mental Health and Related Services Act 2005: A primary care provider means a person who because of his or her relationship with a person, whether that is through kinship, familiarity, marriage or a de facto relationship, has a sense of responsibility for that person and provides care and support for that person, whether or not the person lives with that person.

These definitions characterise carers in a variety of ways, including their relationship to the person being cared for (a familial relationship, a partner, a friend), how they have been identified as a carer (by virtue of their relationship or nominated by the person being cared for), and the care provided (financial or social support, decision making, managing the care). This diversity regarding who is a carer, and what is involved, complicates efforts to engage carers and reach a shared understanding of their role in the engagement process.

The growing international policy imperative to engage and work with service users and carers and to take account of their views seems to imply that their views are compatible and that they are seeking the same outcomes. In reality, balancing the views and needs of service users with those of their carers is not straightforward. The needs of service users and the needs of carers should not be conflated; it is important to understand the individual support needs of both parties. ‘Carers’ and ‘service users’ should be recognised as separate groups whose views will sometimes differ and even come into direct opposition.

It should also be recognised that the categories of ‘carer’ and ‘service user’ are not mutually exclusive, and many service users are also carers. Service users, family members and carers will have experiences of the same mental health services from different perspectives, and so it is likely that there will be overlap in their opinions and perceptions.

Engagement

As with the term ‘service user’, many terms are used in addition to ‘engagement’. These include involvement, both stakeholder involvement and patient and public involvement (PPI); participation; empowerment; and co-production.

The choice of term may imply a particular philosophy or emphasis. Co-production could represent a commitment to delivering services through an equal and reciprocal relationship between professionals, practitioners, service users, carers and other stakeholders. While PPI might be argued to focus on shared decision making. Nevertheless, each of these terms generally refers to involving individuals or groups with an organisation or its activities.

Whatever the language used, a disconnection has been identified between the rhetoric of user engagement and involvement advocated in international mental health policy and the tendency and capacity to adopt these practices on the ground.

A recent analysis of the term ‘service user involvement’ in 134 papers suggests a number of key attributes, antecedents and consequences of service user involvement in the mental health field and has informed a proposed definition of the concept. The authors put forward five key attributes of service user involvement within the context of mental health care:

1. A person-centred approach
2. Informed decision making
3. Advocacy
4. Obtaining service user views and feedback
5. Working in partnership.

This report emphasised the importance of the policy context and the historical background in creating a facilitative

18 Harris and White (2013).  
20 Bee, Brooks, Fraser, and Lovell (2015).  
context for service user engagement. A general assumption of willingness to become involved on the part of the service user was noted: this is problematic because not all service users will necessarily want to be involved in all (or any) of the opportunities for engagement. Both positive and negative consequences of service user involvement were discussed in the papers analysed, with negative consequences typically being associated with circumstances where the motives for involvement were 'not right' or the service user involvement was tokenistic. Based on their analysis the authors proposed the following definition of service user involvement:

"An active partnership between service users and mental health professionals in decision making regarding the planning, implementation and evaluation of mental health policy, services, education, training and research. This partnership employs a person-centred approach, with bidirectional information flow, power sharing and access to advocacy at a personal, service and/or societal level."

(Millar et al, 2016, page 216).

The National Strategy for Service User involvement in the Irish Health Service (2008-2013) defines involvement as:

'A process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change ... We would also see a role for service users in monitoring health service performance.'

(Health Board Executive 2002) (Page 6).

There is considerable overlap in the definitions outlined above. However, it is important to note important differences which may have a significant impact on how ‘engagement’ is enacted. The definition put forward by Millar et al (2016) emphasises partnership and bi-directional information flow, whereas the National Strategy speaks of 'a process by which people are enabled'. This may reinforce assumed power differentials between service users and service providers with the assumption that service providers are responsible for doing the ‘enabling’.

This report adopts the terminology used by the Mental Health Engagement Office, the terminology that appears in the Report on the Listening Meetings (2015) and Partnership for Change, the report of the Mental Health Reference Group (2016). Accordingly, the terms service user and engagement are used. However, the overlap with other relevant terms is noted.

Issues to attend to

Service user engagement in any context requires attention to key factors; some of these require particular attention in the context of mental health services. The literature suggests that the following issues should be attended to:

- **Power imbalances**: Significant power imbalances exist between mental health service users and the services they utilise, including the professionals working within them. Co-production has been seen as a way of addressing this power imbalance by designing and delivering services in partnership. Efforts in several countries to change community attitudes and improve mental health care in partnership have produced resolutions and guidelines, but their wide use and the structural changes they call for are yet to be achieved. There appears to be little evidence of power sharing and limited commitment to the necessary resources to promote partnership involvement. Unless power imbalances are addressed, service user involvement may be more meaningful in theory than in practice.

- **Attitudes of staff**: Attitudes of staff can be both a barrier to and enabler of engagement, particularly if service user engagement is perceived to be threatening or of little value. Many healthcare professionals have not embraced the idea of partnership for a range of reasons. Some staff may have reservations and doubts about the involvement of service users. They may feel that users are not interested in or able for engagement due to illness and severe problems. They may find it difficult to motivate clients, or that their knowledge already grow enough about their clients and their experiences and so further engagement is unnecessary.

22 Wallcraft et al. (2011).
23 Diamond et al. (2003).
24 Ocloo and Matthews (2016).
25 Diamond et al. (2003).
Organisational-level influences:

- **Tokenism:** The engagement efforts described in the literature to date have primarily represented the lowest levels of involvement, where service users receive information from services or are consulted on predetermined topics. Consultation is more often the norm than collaboration. Although there may be more service user groups than there used to be, their influence appears to be limited. Internationally, there is evidence to suggest that patient representatives are struggling to influence decisions and are expected to conform to the existing system. Most reviews of the impact of service user engagement activities find limited results, beyond the impact on the individuals involved in the engagement activities. This may result from a tendency to involve a narrow group of individuals in engagement activities rather than a representative group, and the difficulty in ensuring service users have an instrumental, rather than symbolic, role.

- **Changing role of service user:** There continues to be confusion about the purpose and meaning of user involvement. It has been argued that true service user participation and engagement confers increased rights and responsibilities to service users compared to the traditional role of being a patient. This can be difficult for services to reconcile with their model of operating.

- **Individual-level influences:** Many factors influence people’s ability to participate. These include their beliefs about role (their own and the role of others), health literacy, education, organisational policies, practices, cultural, societal and social norms as well as regulation and policy. Issues relating to inequality, discrimination and social inclusion prevent many from participating. People with mental illnesses are among the most socially excluded in society. Additionally, aspects of mental health problems can hinder participation. There is a need for support in order to exercise right to influence services for service users.

- **Organisational-level influences:** It has been argued that true engagement and participation must be part of the fabric of mental health services and affect every aspect of mental health provision. Organisations need a clear policy about partnership, and staff should be aware of existing policies and how to implement them. Organisations may have a shortage of awareness, knowledge, skills and other capacities or of financial, organisational, staff and other practical resources to support the process.

- **Diversity and representation:** Service users are a heterogeneous group. Marginalised groups such as Travellers, prisoners or ex-prisoners, people with disabilities, and lesbian, gay or transgender people tend to be over-represented in the mental health service user population (possibly because their marginalised status can precipitate mental health problems), yet remain under-represented in engagement and participation activities. Engaging a diverse range of people is challenging. Often, only a few selected individuals are involved and this leads to criticisms of exclusivity and tokenism, particularly if those involved are handpicked representatives that conform to the workings of the organisation.

- **Lack of action:** If people are repeatedly asked for their opinion and actions are not followed through, there is a risk of them becoming disillusioned. This may lead to disengagement and opting out of participation in clinical and strategic activity in the future.

- **Right to opt out:** Not all service users may choose to be involved. The promotion of service user engagement needs to be balanced with the right of service users not to participate, or to withdraw when they want to.

### Levels of Service User Engagement

A range of models outlining service user, family member and carer levels of engagement, has been outlined in the literature. There is a good deal of overlap in these models, but there are also important differences.

A frequently cited framework for user involvement in mental health services describes four main levels of engagement:

- **Interactions between service users (self-help)**
- **Interactions between users and health professionals (individualised care planning)**
- **Local service management opportunities**
- **Service planning.**

The application of this framework in a UK setting identified a growing range of involvement initiatives, and the majority of activities identified remained at a tokenistic or instrumental level.

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26 Ocloc and Matthews (2016).
27 Tait and Lester (2005).
28 Horrocks, Lyons, and Hopley (2010).
29 Ocloc and Matthews (2016).
30 Horrocks, Lyons, and Hopley (2010).
31 Diamond et al. (2003).
32 Elstad and Eide (2009).
33 Ocloc and Matthews (2016).
34 Elstad and Eide (2009).
35 Tait and Lester (2005).
36 Wallcraft et al. (2011)
37 Roe and Davidson (2005)
38 Ocloc and Matthews (2016).
lip-service level, with service users seen primarily as subjects of consultation rather than agents in control. These four levels can also be broadly viewed as encompassing the three levels described by Crepaz-Keay (2014), namely the individual level, the operational level and the strategic level:

- **At an individual level**, service users are involved in their own care. This encompasses self-help and individualised care planning as described by Peck et al. (2002).
- **At the operational level**, service users are involved in the running of services or organisations.
- **At the strategic level**, service users are involved in policy development and the planning, monitoring, commissioning, and governance of mental health services.

These three levels resemble the three levels of engagement (termed involvement) described in the National Strategy for Service User Involvement in the Irish Health Service (2008-2013). In the strategy, levels of involvement are categorised as:

- **Individual**: service users’ involvement in their own care
- **Community**: involvement in local service delivery and development
- **National**: strategic policy informed through involvement of service user organisations in partnership with health care professionals.

This review focuses on engagement at the operational/community levels and the strategic/national levels, rather than at the individual level of engagement/involvement of service users in their own care. Engagement of the individual in their own care is an important area for services to consider regarding service user engagement, and there is a large body of literature dealing with this topic.

This level of engagement, however, is not within the remit of the current review.

This review considers involvement in local service management and service planning, as well as service user involvement in policy development, monitoring, commissioning and governing. These levels reflect the areas of work of the HSE Mental Health Division National Structures for Engagement with Service Users, Family Members and Carers. The Partnership for Change report describes these levels as ‘local and area engagement’ and ‘national engagement’. The structures recommended by the reference group for engagement at the local and area level include:

- Local forums
- Area forums
- Area lead for mental health engagement
- Additional mechanisms for engagement.

At the national level, the reference group recommended the following structures:

- The Head of Mental Health Engagement
- The Mental Health Engagement Office
- The Strategic Advisory Group to the Head of service user, family member and carer engagement.

These structures are illustrated in Figure 1. The local forum is primarily comprised of service users, family members and carers (with others included by invitation from the forum through the chair/secretary). The area forum includes these in addition to service providers statutory, voluntary and community based service providers and groups.

Researchers from New Zealand and Norway have noted that service user engagement appears to be more commonly achieved at the individual level rather than at the wider organisational level.

Similarly, in a survey of service user and professional perspectives from the UK, both service users and professionals were least likely to have experience of service user engagement around commissioning services. This could be due to the highly specialised nature of commissioning processes within mental healthcare settings, but the report also suggests that it may reflect the limited opportunities to become involved in this area of user engagement.

**Figure 1** HSE Mental Health Division National Structures for Engagement with Service Users, Family Members and Carers

40 Tait and Lester (2005).
41 The titles of these recommended structures have changed since the original report. This review adopts the current titles.
42 Kent and Read (1998).
44 Omeni, Barnes, MacDonald, Crawford and Rose (2014).
Figure 1 HSE Mental Health Division

National Structures for Engagement with Service Users, Family Members and Carers
2. Models of Service User Engagement
Several models of service user engagement (or involvement or participation) are proposed in the literature. Arnstein’s (1969) ‘ladder of involvement’ (see Figure 2) has widely been used as a theoretical framework to inform the development of service user and carer involvement, and engagement in fields such as mental health, social work, and beyond. It extends from ‘manipulation’ and ‘therapy’ on the bottom rungs of the ladder, to ‘delegated power’ and ‘citizen control’ on the top rungs. Similar ladders have been developed for child and youth engagement (see Hart, 1992, with ‘shared decisions’ at the top rung), for mental health training in higher education (see Tew et al., 2004, which has partnership at the apex), service user research (Sweeney and Morgan, 2009, with ‘control’ at the top) and sustainability (see Pretty, 1995, with ‘self-mobilisation’ on the top).

Such models tend to imply that there is a linear progression towards meaningful involvement (or whichever underpinning construct the model is based on, see Figure 1). However, it is important to note that involvement can be meaningful at lower levels and that the impact of service user engagement is likely to be greatest when services users influence all levels of service from policy development to delivery.

Figure 2 Arnstein’s ladder of involvement (adapted from Arnstein, 1969)

User engagement, involvement and empowerment are complex phenomena in any setting. Engagement is more likely to fail when expectations and engagement methods do not match. Therefore, the reliance on specific conceptualisations of engagement as illustrated in Arnstein’s ladder, may prove unhelpful. An approach to engagement involving dynamic structures and processes, that are developed and agreed by both participants and non-participants, may be more useful. It has been proposed that users must have capacity to act independently, to make their own free choices, and the ability to shape the methods used for their involvement. These may change over time and so flexibility is required.

In addition to ‘ladder’-style models of participation, other useful and more dynamic frameworks have been put forward. For example, in the field of healthcare, Carman and colleagues (2013) have proposed a framework for understanding the elements of patient and family engagement and developing interventions and policies. This framework, adapted to the mental health services context in Figure 3, characterises engagement as a continuum, and illustrates the extent to which patients are involved in decision making. It suggests that a greater impact could be achieved by implementing interventions across multiple levels of engagement; interventions that increase engagement at the policy-making level may increase engagement or improve outcomes at the levels of direct care or organisational design and governance. It also suggests that interventions can be designed to address the factors that influence patient engagement beyond targeting patient factors (like knowledge or motivation). Interventions could also address organisational and societal barriers to engagement.

Models of co-production and co-design are increasingly being proposed as a means of addressing power imbalances through designing and delivering services in more democratic, equal and reciprocal relationships between professionals, people using services, their families and their community. Six basic principles underpin co-production models:

1. Recognising people as assets
2. Building on people’s existing strengths
3. Reciprocal relations with mutual responsibilities and expectations
4. Peer support and engaging a range of networks inside and outside services
5. Removing tightly defined boundaries between professionals and recipients to enable shared control and responsibility
6. Shift from delivering services to supporting things to happen.

**Figure 3** A framework for understanding the elements of service user, family member and carer engagement (adapted from Carman, et al 2013, Peck et al, 2002, Crepaz-Keay, 2014, and the National Strategy for Service User Involvement in the Irish Health Service 2008-2013).
3. Mechanisms for engagement
3. Mechanisms for engagement

A review of the evidence of service user engagement in health services\(^\text{49}\), commissioned by the CEO of the HSE and the then Department of Health and Children (DoHC) in 2008 noted that:

There are many different ways of listening to people and involving them. And the key message coming from the literature is that no single method will suffice”

(page 21).

Service users want to be engaged, but not necessarily extensively or on every issue. Rather, they want to be engaged appropriately, and to have a real influence. Different mechanisms of engagement are therefore required depending on the purpose. When it comes to engagement at operational and community levels, a range of potential mechanisms exist. When the focus on engagement and involvement shifts from the individual to the operational level, the nature of power imbalances changes:

The interface becomes that between an individual mental health service users and an organisation. To redress these power imbalances and make involvement effective, the organisation and its behaviour needs to be broken down into manageable pieces”

(page 26)\(^\text{50}\).

In his work to develop consensus on indicators of effective involvement in mental health services, Crepaz-Keay (2014) notes the several mechanisms for involvement at the operational and strategic levels as identified in the literature. These are often overlapping and are not mutually exclusive. Table 1 outlines these mechanisms. These mechanisms vary in terms of intensity, the skillset required for implementation and the degree to which service users control the process:

- **Intensity** refers to the effort required by service users and services, with *low* involving less time and little accommodation of service users, *medium* requiring moderate effort and some modifications to usual practices, and *high* requiring new ways of working and substantial time commitments.

- **Skill** refers to the level of expertise required to facilitate or implement the engagement activity. Even at *low* levels particular facilitation and interpersonal skills are required, *medium* suggests that some specific training has been received, and *high* reflects a practitioner specifically trained/qualified in the approach.

- **Degree** refers to the extent of role of the service users in the engagement, with *low* reflecting approaches where service users are informed only and have limited control and influence, *medium* incorporating consultation and feedback, and *high* representing approaches which involve greater levels of collaboration including co-design and co-delivery.

If mechanisms are categorised as ‘low’ on any or all of these criteria, it does not mean that the service user engagement activity can necessarily be easily implemented. In fact careful consideration of the purpose and use of any feedback is still required, especially since the risk of tokenism may be increased due to the apparent simplicity. Steps to avoid this must be taken.

Mechanisms categorised as ‘high’ on all these criteria also are not necessarily better – but they do require significant effort, skill and flexibility to successfully implement. In all cases the purpose of the engagement and the desired outcomes should be clear to all involved. The table also describes the purpose for which each mechanism is most appropriate.

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\(^{49}\) McEvoy, Keenaghan and Murray (2008).
\(^{50}\) Crepaz-Keay (2014).
<table>
<thead>
<tr>
<th>Mechanism</th>
<th>Skill</th>
<th>Intensity</th>
<th>Degree</th>
<th>Purpose</th>
<th>Points to Note</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regular meetings for service users to attend to get involved</td>
<td>Low</td>
<td>Low</td>
<td>Low</td>
<td>Inform and consultation</td>
<td>Meetings tend to favour those who are more articulate and confident in group settings. Some service users may not be comfortable contributing in a meeting context.</td>
</tr>
<tr>
<td>Service users attend the governing body</td>
<td>Low</td>
<td>Low</td>
<td>Low</td>
<td>Inform</td>
<td>It should be clear what the role of service users is if they are attending the governing body – Are they there solely to observe? Will their views be sought? What will change on the basis of their attendance?</td>
</tr>
<tr>
<td>The service's operational meetings include one or two service users</td>
<td>Medium</td>
<td>Medium</td>
<td>Low</td>
<td>Inform and consultation</td>
<td>It is generally recommended that more than one service user is included in order for service users to be able to support each other.</td>
</tr>
<tr>
<td>Decision-makers from services visit service users at service user-led meetings</td>
<td>Medium</td>
<td>Medium</td>
<td>Low</td>
<td>Inform and consultation</td>
<td>Service users can control the agenda; but frustration can result if it is not clear how decision makers will use the information or feed it back.</td>
</tr>
<tr>
<td>Independent service user panel</td>
<td>Medium</td>
<td>Medium</td>
<td>Medium</td>
<td>Consultation and decision-making</td>
<td>Panels are a resource for the body that establishes them, rather than a service user developed initiative. They have a clear purpose, but their close relationship to the service might raise questions regarding the validity of findings</td>
</tr>
<tr>
<td>Meetings structured to ensure equality of involvement for all participants</td>
<td>High</td>
<td>High</td>
<td>Medium</td>
<td>Enable participation and shared decision-making</td>
<td>Structures such as the Nominal Group Technique and Delphi process are designed to avoid problems inherent in traditional meetings</td>
</tr>
</tbody>
</table>
Learning from Key Guidelines and Reviews

A number of jurisdictions and organisations have developed guidance on service user, family member and carer engagement in general, and for specific issues of concern related to service user engagement. See Appendix 1 for examples of key guidelines, evidence reviews and recommendations. There are several important points to note from these documents:

- There is mixed evidence on the impact of service user, family member and carer engagement and public involvement.
- There have been calls for significant development of the evidence base on engagement and involvement, particularly regarding the reporting of user activity and its impact\footnote{Mockford et al (2012)}.
- Service users, practitioners and researchers have developed best practice guidelines on service user, family member and carer engagement and many of these have been developed using collaborative approaches.
- How involvement is valued is a significant issue and raises questions about how the role of service users in engagement initiatives is perceived. The idea of valuing involvement encompasses not only paying for involvement, or at least covering of out-of-pocket expenses for service users, but also how services recognise service user engagement and the value placed on the outcome of engagement activities.
- Service user engagement is typically seen as service users taking up an active role, rather than merely being consulted or receiving information.
The methods used in research about service user engagement do not tend to match the stated aims of research and the resulting research is ‘on’ rather than ‘with’ service users.

There are a range of reasons why services wish to pursue user engagement – the ‘why’ should be understood by all those involved and should match the methods used:

» it can be seen as ‘the right thing to do’ and a fundamental citizen’s right

» it can be seen as having therapeutic value, contributing to empowerment, quality of life and recovery

» it can be seen as useful in enhancing the quality and accessibility of services by making them more responsive to the needs of the service users (this is the most relevant reason to the present review)

» it can be used for political (arguably tokenistic) reasons to meet governmental or funding requirements or to increase the initiative’s perceived legitimacy.

Thematic Analysis of Guides to Service User Engagement

A number of guides to service user, family member and carer engagement have been developed through engagement with service users. Five well regarded guidelines, standards and recommendations were reviewed in detail to extract common messages:


Although the intended audiences for these guidelines and recommendations differed somewhat (from general audiences, to service users, to staff and organisations) there was considerable overlap in the general themes addressed. These are practical recommendations which can and should be taken into consideration prior to initiating and engagement activities.

The recommendations are synthesised under the following headings:

☐ Commitment to the approach
☐ Shared understandings
☐ Representation
☐ Variety and flexibility
☐ Support
☐ Monitoring.

The following section outlines these recommendations in further detail alongside findings from research evidence on service user engagement.

52 This report has been superseded by others, but the recommendations remain valid and useful.
4. Service User Engagement in designing, delivering and evaluating services
4. Service User Engagement in designing, delivering and evaluating services

This section distils learning from studies on a variety of mechanisms which integrate service user engagement into the design, delivery and evaluation of services. It is important to note that there is limited research and evidence on this topic, but ongoing research efforts are attempting to address this. Nevertheless, there are some strong and consistent messages apparent across the literature and research.

Relevant research was identified through electronic searches of relevant databases, journal articles and websites. Relevant key search terms were used including ‘Service User’ (or consumer or patient or public, etc. and/or carer) and ‘Engagement’ (or participation or involvement or co-production, etc.), and ‘Mental health services’ (or mental health setting or care). Sources were selected on the basis of quality, relevance, utility and applicability to the Irish context. The literature was thematically organised according to headings developed to aid in the extraction of key learning and recommendations for practice.

The findings presented here incorporate the findings from the thematic analysis of guides to engagement, and the findings from the literature review. Additionally, each section contains links to recommendations from the Partnership for Change Report of the Mental Health Reference Group to contextualise the findings to the work of the MHD and the Mental Health Engagement Office. The themes are organised under four headings:

- Why? Understanding the value and purpose of service user engagement
- Who should be engaged?
- How should engagement happen?
- Is it making a difference?

1. Why? Understanding the value and purpose of Service User Engagement

A consistent message was identified in the recommendations and literature review relating to the importance of service providers, staff and service users sharing an understanding of the value and purpose of service user engagement. The guidelines reviewed emphasised the need for a commitment to the approach and the need for shared understandings.

A commitment to service user, family member and carer engagement within the MHD is demonstrated by the work that has been undertaken on bringing together the Mental Health Reference Group to deliberate and decide the structure of engagement required to ensure that service users, families and carers are central to the design and delivery of mental health services. The resulting Partnership for Change report emphasises that service user engagement is not a one-off event; it is an ongoing process which must be continuously updated and refined.

Common recommendations from the analysis of engagement guides

- **Service providers must be committed to the approach:** Services should recognise the work involved in initiating and supporting service user engagement. There needs to be a commitment to service user engagement, and the principles underpinning such approaches.

  This requires a shared understanding of the purpose and desired outcomes; an appetite to listen to service users and respond to their needs; an acknowledgment of the power differentials that exist (and actions to minimise these); an openness to engaging in a variety of ways using a range of methods; a readiness to support staff and service users to engage effectively; and a willingness to prioritise the views of service users. Engagement should be planned, with sufficient resources made available.

- **Service providers, service users, family members and carers should have shared understandings:** The purpose of engagement activities should be agreed from the outset, with a shared understanding of why service users and carers are involved, and the different roles they adopt. Both staff and service users should know what to expect of each other in the engagement process. Opportunities to be engaged should be shared through a variety of channels, with the potential for influencing, and the limits of this potential, clearly communicated. Information should be readily shared with all engaged parties, and service users should be asked how they would best like to receive feedback. Service users should know how the information they share is used and with whom it is shared.
Evidence from the literature

- Service providers must understand why the service they provide should involve service users in the design, delivery and evaluation of their services. This understanding should inform the methods used for service user engagement, and the methods used to evaluate service user engagement.

The evidence suggests that many service providers are yet to be convinced of the value of service user engagement. Research on service user engagement in both London and Norway has suggested that service user experiences are not necessarily seen as valid sources of input to inform the work or improvement efforts of service providers. This is related to a perception that either the service users involved in the engagement activities are not representative of the wider service user group, or that they do not tell the professionals anything that they do not already know.

- Service providers must have a shared understanding of the role of service users, both in engagement efforts and in the service as a whole. This requires moving beyond a view of service users as patients or consumers of services to one of citizens with human and democratic rights. This view of service users should also influence the mechanisms of engagement chosen and how any recommendations identified are acted on.

Achieving a shared understanding of the role of service users may be difficult. It may challenge how service providers see themselves and their own roles, as well as how they measure the success, efficiency and effectiveness of their services. However, this is an important step in developing and implementing truly service user focused services. Service providers should identify any taken for granted assumptions about service users and their journey through the services and challenge these assumptions.

Reconceptualising the role of service users will likely involve moving beyond a focus on clinical outcome measures to outcomes that are identified as meaningful and relevant to service users. Two international projects – the Study of Consumer Priorities (SCOPE) for Research, and a Roadmap for Mental Health Research in Europe (ROAMER) – along with various country-level efforts such as the Survivor-Controlled Research foundation in the UK are examining service user priorities. They have shown how service user priorities can differ (sometimes slightly, sometimes profoundly) from the issues prioritised and targeted by service providers, practitioners and researchers.

- Service providers must have a clear understanding of their own role/roles in service user engagement activities. Service providers are generally accustomed to being seen as the experts with regard to mental health care. When involved in service user engagement, service providers must recognise that they are no longer the experts, or at least they are not the only experts with valid viewpoints to contribute. They must be open to hearing diverse opinions and experiences which can be threatening. Service providers may become defensive when hearing critiques of their services. Knowing what to expect and how to interpret service user input can guard against service users feeling attacked. Service providers need support to navigate their role in service user engagement activities.

- Service users should know why they are being involved and how their participation is intended to affect service design, delivery and implementation. This understanding should match the understanding of service providers, and the aims and intended outcomes should be realistically achievable. Ideally, a shared understanding will be built with service providers at the outset of any service user engagement initiative.

- Service users should have access to clear information to facilitate informed understanding. Service users need clear information about the engagement activity. They need to know what to expect and what will be expected of them. They should be involved and informed at all stages of the engagement process. Service users should influence how engagement happens. Service users also need clear, accessible information on how to access support in a timely fashion including financial remuneration.

References:

53 Crawford et al. (2002).
60 Sainsbury Centre for Mental Health (2010).
62 Sainsbury Centre for Mental Health (2010).
2. Who should be engaged?

Both the sets of guidelines and the literature reviewed considered the issue of who should be involved in engagement activities. The guidelines focused on the achieving adequate representation of service users, while taking their needs and wishes into account. Similarly, the literature emphasised the need to open engagement opportunities to all service users, while recognising the importance of minimising potential risks.

The recommendations in Partnership for Change call for wide representation of service users. The Reference group advised that if, for example, a ‘listening meeting’ were to be held, it must be widely advertised and open to everyone in the area with an interest in mental health. This should include service users, family members, carers, service providers, and the general public. Listening meetings are designed to allow those taking part to give their views in an open, transparent and respectful manner in an unstructured format.

**Common recommendations from the analysis of engagement guides:**

- **Service users, family members and carers should be representative of the service user population:** The service users and carers involved in service user engagement should include people from diverse backgrounds and communities, with a focus on reflecting the whole population of service users. Attempts should be made to involve service users and carers separately to capture a diversity of priorities and views. An individual service user should not be expected to represent the views of all service users and carers. Getting appropriate representation will require services to think about a variety of ways of engaging different groups, and working with service users to understand how best to involve them.

- **Evidence from the literature:**
  - All service users should be eligible to be involved in service user engagement activities. All service users should be considered when it comes to service user engagement activities. Clear, transparent procedures for identifying and inviting service users to participate should be in place. All service users should be made aware of engagement opportunities through a range of accessible channels.
  - Special efforts should be made to involve a representative group of service users. This will likely mean targeting ‘hard-to-reach’ service users. Involving service users in the recruitment of other service users has been shown to be effective. If the same group of service users are involved in each engagement activity, service providers should re-think their engagement strategy to reflect a broader range of perspectives.

- **Participation is voluntary.** While all service users should be considered eligible to participate, not all service users will participate, and those who do will not necessarily want to participate at every opportunity.

- **Service providers must recognise that engagement can pose risks to service users, and they should take steps to minimise these risks.** Risks can include their perceived ability to continue using services due to their participation, and the attitudes of other staff and service users. Service users may find it difficult to continue to use services if they are involved in an evaluation or commissioning process that negatively impacts on their relationship with staff or other service users. Processes to mitigate risk should be established in advance.

- **Staff with the right skills for engagement should be involved.** These skills include flexibility, communication, and openness and they should be valued by service providers and nurtured in staff.

3. How should engagement happen?

The process of engagement was identified as important in both the guidelines reviewed and the literature, with the need for variety in approaches used being emphasised along with the need to adequately support service users and staff for optimal engagement.

The Partnership for Change report emphasises the need for support for service users, family members and carers to build capacity to influence the design and delivery of mental health services through the identification and delivery of the required training interventions. It also recognises the need to develop a range of engagement mechanisms to promote widespread and regular consultation with service users, family members and carers in relation to HSE mental health services at local and national level.

**Common recommendations from the analysis of engagement guides**

- **Offer variety and flexibility:** Service users should have a range of different opportunities to engage and should be able move in and out of involvement when

63 Sainsbury Centre for Mental Health (2010).
they choose to or need to. Service providers will need to be flexible and embrace different ways of working, and should consider how to involve service users who may not usually feel involved. Engagement activities, including meetings, should take account of those involved and should consider reasonable adjustments to meet the needs of service users. This includes scheduling and duration, format and flexibility of meetings or other kinds of contact.

Provide support: Both staff and service users need support and training. Services need to plan for administrative support, supervision and emotional support, with an awareness of likely stresses service users may experience. Training should be used to enable fair involvement and skills development among service users. It should also raise awareness about, and enhance skills needed for, involvement and engagement. Shared training between service users, carers and professionals can help to build a sense of team work. Engagement can be costly for service users, with out of pocket expenses incurred and users are giving their time and expertise. Services need to decide how they will compensate service users, and this needs to be clear to service users.

Evidence from the literature

Services should adopt a rigorous approach when identifying the purpose, aims and objectives of engagement activities. This approach should be transparent, and be informed by the views and priorities of service users. The same rigorous approach should inform the implementation, monitoring and evaluation of the engagement approaches.

Service user engagement opportunities should take a variety of forms. Evidence on service user engagement in research, developing guidance, mental health collaboratives and re-commissioning services demonstrates how different forms of engagement can be used to facilitate input from a range of different service users at different stages of a project. The greater the variety of options available, the broader the range of individuals engaged.

The process of involvement is as important as content. Communication with service users, families and carers should be accessible. Staff should have good interpersonal skills. Documentation and questionnaires should be developed with service users and administered by staff sensitive to the needs of service users, families and carers.

Service users can be involved in engaging other service users. Service users may be better able to engage hard-to-reach service users. Service users are more comfortable expressing negative views, opinions or experiences to other service users. The All Ireland Traveller Health Study Our Geels successfully utilised ‘peer researchers’ in the recruitment of participants and collection of data. Other examples of engaged research are described in the Engaged Research report developed by Campus Engage and the Irish Research Council in collaboration with partners from higher education institutions and community and voluntary organisations.

Service users will need support to engage optimally. Service users benefit from direct support for engagement, which enables them to contribute fully. Relevant support could include patient advocacy services, training to develop skills, confidence building, peer support, and structuring meetings that facilitate service user contribution. Financial support can help to remove both practical and symbolic barriers to service user participation by offering a form of recognition, and reducing the cost of engagement. The process of accessing financial support and remuneration should be clear, convenient, and accessible.

Service providers need to be supported to engage meaningfully. Engagement efforts will flounder if there is a lack of resources, competence, and priority for this type of work. Engagement efforts benefit when an environment is created where professionals and service users work together as equal contributors. However, staff need support to deal with the challenges and implications of genuine engagement and partnership with service users.

Evidence from the literature:

- Services should adopt a rigorous approach when identifying the purpose, aims and objectives of engagement activities. This approach should be transparent, and be informed by the views and priorities of service users. The same rigorous approach should inform the implementation, monitoring and evaluation of the engagement approaches.

- Service user engagement opportunities should take a variety of forms. Evidence on service user engagement in research, developing guidance, mental health collaboratives and re-commissioning services demonstrates how different forms of engagement can be used to facilitate input from a range of different service users at different stages of a project. The greater the variety of options available, the broader the range of individuals engaged.

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References:

- Campus Engage (2016).
Ongoing feedback to service users can help to build and maintain their motivation, trust and confidence. A lack of feedback can make service users feel that their involvement is tokenistic, can make service users feel disempowered, and can discourage future engagement. Services users need to know what difference their contribution makes.

Ongoing monitoring should incorporate measures identified and endorsed by service users. Changing what is measured and reported can change what is valued by service providers. When it comes to monitoring, research points to the need to involve service users in identifying measurements of performance that are meaningful and relevant to recovery outcomes beyond clinical outcomes measures. This is important to keep in mind at the outset of engagement, during ongoing monitoring, and when evaluating impact.

4. Is it making a difference?

Both the guidelines and the literature are clear on the need to establish whether engagement efforts are making a difference. The literature highlights that this is not necessarily an easy process, and it reinforces the need to be clear on the purpose of user engagement in the first place.

The Partnership for Change report recognises the need for ongoing monitoring and evaluation of engagement activities. It notes that consultation and engagement are likely to evolve over time and that it will be important to regularly review and evaluate these at least once every three years. The report indicates that evaluation will focus on specific areas from which definite learning can be drawn to improve the engagement processes.

Evidence from the literature

The impact of service user engagement efforts must be evaluated. This will show the difference, if any, that service user engagement has made. Service users should be involved in the design and implementation of the evaluation where possible and practical. Research suggests that identifying the impact of service user engagement is complex, and studies do not always demonstrate impact. It has been suggested that models of participation focussing on the process of engagement (such as empowerment or partnership models) are easier to evaluate than those focused on outcomes.

Service users and service providers should receive feedback on engagement efforts. Service providers should ensure that service users, family members, carers and staff are made aware of the outcomes of service user engagement efforts, what was learned, what will be done differently, and how their experiences will inform future engagement activities. If recommendations were identified through engagement efforts, but not implemented, the reasons why should be articulated. Information should be given on what is being done to address the issues raised.

The success of service user engagement should be celebrated with service users and staff. Success can encompass a range of outcomes. The recognition of service user engagement, particularly its successes, signals and reinforces value that service providers place on the process.
5. Conclusions

One in four people have a mental health issue so one central figure saying “I have a mental health issue” And then 8 other figures with speech bubbles from 2 of them saying: “So do I”, “Me too”, “That’s me” “My friend too and that’s ok”
5. Conclusions

The MHD is in the midst of a significant shift regarding the role of service users, family members and carers in mental health services. This shift has the potential to transform how services are designed, delivered and evaluated, with a range of potential benefits for service users and service providers.

The findings from this review make it clear that service user engagement is not a quick fix solution. Rather it presents a challenge to some of the perceived needs, norms and assumptions of service providers and policy makers, in the context of a range of other challenges and constraints.

The review has identified four broad questions which the literature suggests need to be addressed for optimal service user engagement. When starting to embed, improve, maintain and monitor service user engagement it is helpful to reflect on how the four key questions identified in this review are currently addressed, and how they will ideally be addressed in the future:

1. **Why engage with service users, family members and carers?** Service providers and service users, family members and carers need to share an understanding of why service user engagement is being undertaken.

2. **Who should be engaged?** The service users, family members and carers involved should be representative of the wider service user population. The service providers and staff involved should have the right skills for successful engagement.

3. **How should engagement happen?** Engagement should take a variety of forms and a range of opportunities for engagement should be available.

4. **Is it making a difference?** Engagement should be monitored and evaluated to ensure that it is having an impact.

Current Irish mental health policy commits to making service user involvement an intrinsic and essential component of service design, delivery and evaluation. Ensuring that genuine engagement is achieved and applied across the board requires concerted effort, and systemic change. This happens gradually, and takes ongoing leadership, commitment and monitoring to maintain progress.

Engagement should not be seen as a one-off event, but a way of working.

The approach needs to be embedded and valued across all areas of mental health services. This requires the implementation of new processes, policies and procedures relating to engagement. It also requires the development of a culture that supports engagement, and the shared understanding of the role of service users in service provision, design and evaluation.

This review has highlighted the importance of staff attitudes for successful service user engagement. However, positive attitudes toward engagement alone are not enough. Both staff and service users need support for engagement to be effective and meaningful. The evidence also suggests that engagement efforts will struggle if engagement is not seen as a priority. This means engagement needs to be properly resourced and supported. The environment, the understanding of the role of service users, the priorities pursued, plans and reports must all recognise and facilitate engagement.

Service providers and staff will likely be interested and positively orientated toward service user engagement. However, the contexts in which they work must support this approach, and their working environment must actively value, prioritise and facilitate service user engagement through policies and procedures. Otherwise, service user, family member and carer engagement will not become a core element of work. Service user engagement must be seen as ‘business as usual’ and an expected way working if it is to become embedded and sustainable.

Service users, families and carers will not be as familiar with organisational structures, processes and policies as service providers. They will need support to effectively share their experiences and recommendations. The system must be open to, and responsive to, service user, family member and carer contributions.

Service users, families and carers will not necessarily want to be involved in every engagement opportunity. It is important to offer variety and flexibility to ensure engagement with as wide a range of service users, family members and carers as possible.

Staff and service providers may not have training in service user engagement, they may not know what to expect from the process, or how to act on service user feedback, recommendations, perceptions and experiences. Staff will need support on how to engage and how to ensure engagement has an impact.
The literature has clearly shown that service user, family member and carer engagement in the design, delivery and evaluation of services and policies is possible. Therefore, it is important to highlight that this review should not be seen as a final word on what works with regard to service user engagement. Rather, it should be seen as a contribution to a conversation with service users, family members and carers, service providers and other stakeholders regarding what could work and how it could work.

References


INVOLVE (2016) *What you need to know about payment: an introductory guide for members of the public who are considering active involvement in NHS, public health or social care research*, Involve: Hampshire


Mental Health Division, Health Service Executive (2016). *Mental Health Division Operational Plan 2016*. Dublin: Mental Health Division, Health Service Executive.


Appendix 1 Key guidance, evidence reviews and impact reviews

Key guidance on involvement:

Key guidance on payment:
- Involve (2011). *What you need to know about payment: An introductory guide for members of the public who are considering active involvement in NHS, public health or social care research*. INVOLVE, Eastleigh.
- Involve (2010). *Payment for involvement: A guide for making payments to members of the public actively involved in NHS, public health or social care research*. INVOLVE, Eastleigh.
- Sheldon, K., & Harding, E. (2010). *Good practice guidelines to support the involvement of service users and carers in clinical psychology services*. British Psychological Society.

Key evidence reviews the challenges of service user engagement:

Key evidence reviews of impact:
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