

# HSE Mental Health Division

## *Partnership for Change* Report of the Mental Health Reference Group



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Recommendations on the structures and mechanisms for Service User, Family Member and Carer Engagement

# Foreword

Anne O'Connor National Director HSE Mental Health Division

## It is with great pleasure that I present Partnership for Change: Report of the Mental Health Reference Group recommendations on the structures and mechanisms for Service User, Family Member and Carer Engagement.

The HSE's Mental Health Division (MHD) is committed to ensuring that the views of service users, family members and carers are central to the design and delivery of mental health services. The national mental health policy, A Vision for Change from 2006, has recommended that service users, family members and carers should participate at all levels of the mental health system and be active partners in designing, planning, monitoring and evaluating our services.

To ensure that appropriate engagement structures and mechanisms were in place, the MHD established the Mental Health Reference Group in August 2014. Their task was to make recommendations on the structures and mechanisms that would ensure engagement with services at both a national and local level for service users, families and carers and the roles required to support these recommendations.

The MHD recently appointed Liam Hennessy as Head of Service User, Family Member and Carer Engagement to ensure the service user, family member

and carer voices would be represented at the highest level in decision-making on mental health services. Liam will lead on the development of these structures of engagement nationally. He will be supported by nine area leads, one in each Community Health Organisation (CHO) area. Both the head and the area leads will fully participate in all decision-making on mental health services at a national and CHO area level.

Engaging service users, their families and carers, is a critical strategy to improving care. The development of these recommendations marks another significant step forward in the process of ensuring that the views and experiences of service users, their families and carers are central to the design and delivery of mental health services.

I am confident that these recommendations will prove to be of enormous benefit to all who use our services and our service providers in the development and promotion of the structures for engagement. These structures will play an important part in the ongoing quest to improve the quality of services provided.

I would like to thank all those involved in compiling this report, in particular the members of the reference group who showed great dedication and commitment to producing their recommendations, which will help shape future mental health services into a more collaborative partnership.

# Executive Summary

## The Mental Health Reference Group recommendations on the structures and mechanisms for Service User, Family Member and Carer Engagement.

In recent years there has been an increasing focus by the mental health services on working actively with service users, family members and carers, as highlighted in the current national policy A Vision for Change: Report of the expert group on Mental Health Policy (Department of Health and Children, 2006) as well as the HSE National Strategy for Service User Involvement in the Health Service 2008- 2013 (HSE 2008) and the Mental Health Division National Operational Policy, service priority for 2016, which is to ensure that the views of service users, family members and carers are always central to the design and delivery of services.

In August 2014, MHD established a reference group to make recommendations on the structures and mechanism for Service User, Family Member and Carer Engagement. The primary task of the reference group was 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.

## The principal recommendations and reflections on partnership-building featured within the report are:

- The role and function of the head of Service User, Family Member and Carer Engagement as a member of MHD.
- The role and function of the nine area leads of Service User, Family Member and Carer Engagement as members of the area management teams with the HSE mental health services.
- Structures and mechanisms for feedback and consultation through local and area forums.
- Capacity building required to support necessary engagement mechanisms and roles.
- The role of the office for the head of Service User, Family Member and Carer Engagement.
- Reflections on the building of partnership by the independent chair and the reference group members.

### **The head of Service User, Family Member and Carer Engagement**

The head of Service User, Family Member and Carer Engagement will be a member of the MHD and this role will include supporting the area leads in their work, developing national engagement structures and leading the office of the head of Service User, Family Member and Carer Engagement.

## Office of the head of Service User, Family Member and Carer Engagement

The work of this office will concentrate on five main functions:

- Advice, support and review in relation to the local and area structures for Service User, Family Member and Carer Engagement.
- Support for the flow of information and data collection to and from the local and area forums.
- Promotion and support in capacity building to help people be active in the engagement structures.
- Delivering best practice and the development of knowledge, expertise and research in Service User, Family Member and Carer Engagement mechanisms and structures.
- Working with others within and across other HSE services to promote Service User, Family Members and Carers Engagement.

### **Establishment of a strategic advisory group**

A strategic advisory group to the head of Service User, Family Member and Carers Engagement will be established by the head in conjunction with the national director to provide independent strategic and policy advice and external perspectives in this area to support the functioning of the head's role.

### **The role of area leads within Service User, Family Member and Carer Engagement**

Senior managers called area leads will be full members of the area mental health management team and their role will include the following activities:

- Engaging with service users, family members and carers (SUFMC) in each CHO area, using a community development approach.
- Developing the structures and mechanisms for engagement at CHO level.
- Presenting the perspective of the Service User, Family Member and Carer Engagement and to represent their views where they have the evidence and the mandate—via the provided structures—as part of the area mental health management team.

### **Establishment of local forums**

An early task of each area lead will be to establish local forums, as described below. Existing structures – such as consumer panels – will feed into this or may form such a local forum. The main purpose of these forums is to allow SUFMC to voice their experiences, raise issues and be consulted and involved in mental health services developments in their areas. Terms of reference and other guidance will be provided and the local forum should have a chair, secretary and a coordinator. Minutes should be taken and circulated.

### **Area forums within the community**

There will be one area forum in each CHO region, made up of service users, family members and carers, nominated by the local forums, as well as local community and voluntary sector representatives and HSE staff. The area forum will be chaired by the area lead.

## Additional mechanisms for engagement

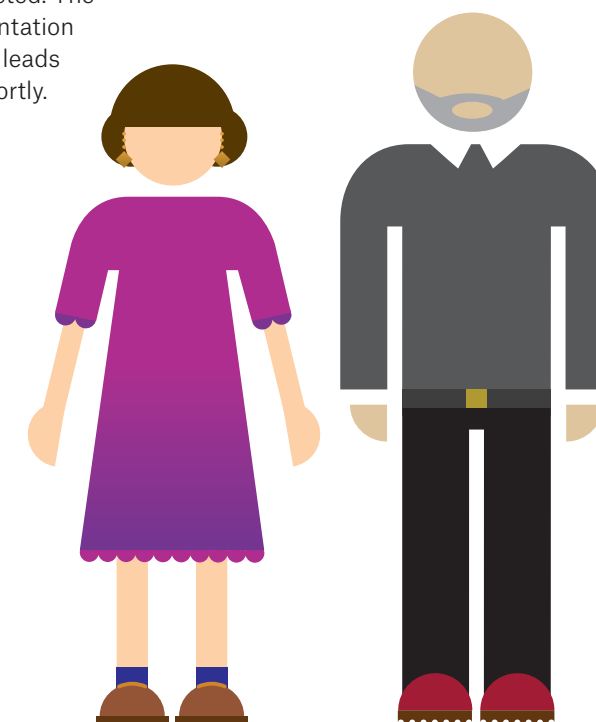
Other mechanisms for engagement—such as surveys, 'listening meetings' and other tools—will be developed by the area lead and will complement national developments.

### **Remuneration and expenses**

The MHD is currently engaged in work to develop procedures for remuneration and expenses reimbursement in relation to SUFMC engagement at a national level.

### **Implementation of the engagement structures and roles**

An implementation steering group, which will oversee the implementation of the new structures has been established by the MHD and the first stage for the recruitment of the head of Service User, Family Member and Carer Engagement has been successfully completed. The second stage of the implementation is the recruitment of the area leads which is due to take place shortly.



# Chapter 1

## The Mental Health Reference Group



*'The establishment of a reference group made up of service users, family members and carers to work directly with the mental health division should be seen as a huge success for the people who have strived for many years to have their voices heard by the mental health service. It's by no means the end goal of achieving a mental health system that works well for those who use it, but it's certainly a pivotal shift in how the mental health division approaches their business.'*

REFERENCE GROUP MEMBER

## 1.1 Introduction

Mental health services in Ireland are undertaking a major change process in line with the recommendations of A Vision for Change, to ensure that service users and their families and carers should be involved at every level of service design and delivery. This is not a one-off pilot initiative nor is it business as usual with slight tweaking around the edges. It is a management-led development of roles, structures and mechanisms to ensure that all parties are effectively and meaningfully involved in planning, implementing and evaluating services. The director of the HSE Mental Health Division appointed an interim head of Service User, Family Member and Carer Engagement in 2014 and subsequently in August 2014 mandated a reference

group of service users, family members and carers and HSE staff to work for a year to develop recommendations for MHD, which has adopted these recommendations and is now in the early stages of implementation.

The purpose of this report is firstly to present the reference group recommendations in the context of how they were developed and secondly to identify the key learning from how the reference group worked and how this learning can be applied to the establishment and continuing development of the new structures for working in partnership to design, plan, deliver and evaluate mental health services.

The Office for Service User, Family Member and Carer Engagement commissioned the reference group independent chair, Jane Clarke to write this report. As well as the work of the reference group this report includes the work of the chair and the views of the members.

Jane Clarke is an independent management consultant and facilitator with thirty years experience working with organisations in the public and community and voluntary sectors. She has worked extensively in health care as well as with a wide range of organisations engaged with social justice and human rights. Jane supports organisations to develop their effectiveness in achieving their goals, with an emphasis on leadership and collaborative teams. Her areas of expertise include organisational development, community development, supporting change, strategic planning and review, management and leadership development, governance, team building, conflict resolution, group work and facilitation.

The membership of the reference group consisted of nine service user representatives and four family and carer representatives. It was originally intended that the group would have a membership of twelve, but due to the illness of one member for an extended period, an additional member was recruited to the group.

The recruitment and selection process to the reference group was designed to be independent and transparent. Expressions of interest for membership of the group were sent to all statutory, voluntary and community mental health service providers, mental health teams, consumer panels and to those

who attended the listening meetings in 2014. SUFMC were invited to apply for membership by written application. The selection panel consisted of the interim head of Service User, Family Member and Carer Engagement, a national HSE HR representative, a HSE representative from the National Advocacy Office and a service user representative from the United Kingdom. The selected members had extensive experience of involvement in service user, family member and carer engagement, either nationally or locally.

The members of the group were:

**Aaron Galbraith**

**Anne Foley**

**Anne Tiernan**

**Aoife Price**

**Bernadette Bushe**

**Brian Hartnett**

**Colette Nolan**

**Joan Higgins**

**John Kidney**

**Madge Fogarty**

**Maire Duffy**

**Michael Ryan**

**Rory Doody**

The group had an orientation day on 14 August 2014, and met sixteen times between then and July 2015. (See Appendix 7 for list of meeting dates).

The group was supported in its work by staff from the MHD, HSE: Catherine O’Grady, Project Manager, Gerry Maley, Business Manager to the Head of Service User, Family Member and Carer Engagement and by Valerie Greville and Valerie Doyle, Administrative Support. Tony Leahy, Senior Operations and Improvement Manager also provided support and information in response to requests from the group.

*‘I was left with a sense of hope that this might not only be a “one-off” experience but could, with appropriate support, also be replicated at local and regional level’*

REFERENCE GROUP MEMBER

## 1.2 Background to the Mental Health Reference Group

*A Vision for Change*, published in 2006, is the strategy document that sets out the direction for mental health services in Ireland. It describes a framework for building and fostering positive mental health across the entire community and for providing accessible, community-based, specialist services for people with mental illness. Particular emphasis is placed on the need to involve service users and their families and carers at every level of mental health service development and delivery from decision-making at an individual level, through individual recovery or care plans (ICPs) to the design, development and delivery of local services and national policy. *A Vision for Change* is underpinned by the principle of partnership, meaning that service users, family members and carers (SUFMC), those working in mental health services and the wider community should be involved in planning and delivering mental health services.

There is increased recognition, nationally and internationally, of the importance of involving service users in the development, delivery and evaluation of health services.

This is reflected in the National Strategy for Service User Involvement in the Irish Health Service 2008–2013, which was developed by the HSE and the Department of Health and Children to ensure a systematic and consistent approach to service user involvement across health and social services.

In line with *A Vision for Change*, the Mental Health Division’s Operational Plan 2015 sets out the inclusion of the views of SUFMC as central to the design and delivery of mental health services. One of the five service priorities of the MHD is to ensure the views of service users are central to the design and delivery of services. The plan identifies two key goals to achieve this service priority:



Build capacity of service users, families and carers to influence the design and delivery of mental health services through the identification and delivery of the required training interventions.

Develop mechanisms for the participation of service users, families and carers in the decision-making processes of mental health services at local and national levels by the full establishment of the office of Service User, Family Member and Carer Engagement as an integral component of the MHD and the appointment of a service user member on each area mental health management team.

MHD established the Mental Health Service Users, Family Member and Carer Reference Group with the following purpose as set out in the Terms of Reference. (See Appendix 1):

To deliberate and engage on issues of concern to service users, family members and carers in relation to the planning, design, delivery and evaluation of HSE mental health services.

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.

To engage on measures to develop the capacity of service users, family members and carers to participate in the planning, design, delivery and evaluation of HSE mental health services. are central to the design and delivery of services.



## 1.3 Evidence for engagement

In recent years there has been an increasing focus by the mental health services on working actively with service users, family members and carers as highlighted in current national policy: A Vision for Change: Report of the Expert Group on Mental Health Policy (DOHC, 2006); the HSE National Strategy for Service User Involvement in the Health Service 2008-2013 (HSE 2008); and the Mental Health Division National Operational Policy, Service Priority for 2015: to ensure that service users families and carers are central to the design, planning, delivery and evaluation of services.

The need for good engagement is now widely recognised as a critical ingredient for a high-quality health care system. Evidence increasingly suggests that engagement can be a pathway towards achieving the goals of better quality of care, greater cost efficiency and improved population health (Carman, 2013).

Service user, family member and carer involvement needs to be recognised as a measure of quality that can improve the outcomes for the mental health services and any quality improvement programme needs to begin with those who use these services and needs to be viewed through their eyes (Coulter, 2012).

Collaborative partnerships are required to move from what has been viewed as a traditional 'paternalistic' model of care to one that is person-centred and rooted in the values of empowerment and recovery, which should aid the personal journey to empowerment, while also assisting those involved with the major challenge of influencing the agenda, policies and services of statutory service providers (Brosnan 2014).

Staff engagement will be instrumental in developing these partnerships. Engaged staff raise the measures of the quality of care. 'Highly engaged staff are more likely to bring their heart and soul to work, to take the initiative, to "go the extra mile" and to collaborate effectively with others.' (Collins, 2014).

Working collaboratively to actively engage service users, family members and carers in dynamic and meaningful roles at all levels of the organisation will require major organisational and cultural change. Strong committed senior leadership will help to bring about this change and provide the opportunities necessary to assist in promoting and sustaining it (Coulter, 2012).

Continued research will be needed (Higgins & McDaid, 2014) on the impact of engagement to outcomes, including improved health, quality, cost and staff satisfaction.

## Chapter 2

# Reference group recommendations to the HSE Mental Health Division



*'We accepted that we all had valuable opinions and where they differed we listened and accepted those differences, but we worked together to create recommendations which will help change mental health services in Ireland forever.'*

REFERENCE GROUP MEMBER

## 2.1 Introduction

This chapter presents the reference group recommendations for local and area engagement and national engagement with service users, family members and carers, beginning with the local structures and mechanisms for engagement, local and area forums through to the national structures. Supporting these engagement structures are a number of specific positions—the head of Service User, Family Member and Carer Engagement and nine area leads.

### **Local and area engagement**

The reference group recommends that every CHO establishes the following four structures for engagement with service users, family members and carers.

- Local forums.
- Area forums.
- Area lead for Service User, Family Member and Carer Engagement.
- Additional mechanisms for engagement.

The recommended structures for engagement are based on a 'grass roots' approach, with local forums established that can gather

the views of service users, family members and carers from individuals, community and voluntary groups.

The local forums link with the area forum—one per CHO—chaired by the area lead.

The area lead is a member of the area mental health management team.

The additional mechanisms will be developed over time to gather the views of service users, family members and carers.

### **National engagement**

The reference group recommends that the local and area engagement is supported by three main national structures:

- Head of Service User, Family Member and Carer Engagement.
- Office of the Head of Service User, Family Member and Carer Engagement.
- Strategic Advisory Group to the Head of Service User, Family Member and Carer Engagement.



## Local Forum

One of the early tasks of the area lead<sup>1</sup> of Service User, Family Member and Carer Engagement, in conjunction with the head, will be to examine what structures and mechanisms for engagement already exist and to develop a plan with all stakeholders to support the development of these, in line with local needs.

When initiating, developing and supporting local engagement with service users, family members and carers consideration should be given to:

- Pre-existing mechanisms or structures for local engagement.
- Positive or negative experiences of engagement to date.
- The number of stakeholder organisations, both statutory and voluntary, and their level of commitment to Service User, Family Members and Carer Engagement.
- The level of leadership and capacity amongst SUFMC.

The office of the head of Service User, Family Members and Carer Engagement will provide guidelines for how local and area forums, and additional mechanisms for engagement should be established.

In addition, the *HSE Best Practice Guidelines for Establishing and Developing a Service User Panel within a Health Setting* are proposed by the reference group as a useful resource when initiating or developing local forums.

When establishing the local forums the reference group recommends that they are organised in line with

service sectors as set out in *A Vision for Change*, with one local forum serving a population covered by two adult sector teams (therefore approximately 100,000 population) with consideration given to geographical factors.

The membership of local forums should be service users, family members and carers and others may be invited to attend meetings. However, any representations made to the area lead or forum must be those of the service users, family members and carers.

The reference group recognises that some areas may wish to establish or maintain consumer panels or equivalent groups such as a 'local mental health network', a 'local mental health alliance' or other groupings. The reference group wishes to respect the excellent work that continues in many communities. In such circumstances all groups should have the opportunity to be represented at local forums and should follow the same access routes as other individuals and groups.

### **Purposes of the local forums**

The local forums will provide a space and opportunity for local service users, family members and carers to voice their experiences and raise issues. They will facilitate the local mental health stakeholders to work collaboratively to resolve issues and to improve the experience of all parties. Where appropriate, these forums will also provide input to community mental health teams from the service user, family member and carer perspective. Such forums will also advocate on behalf of service users, family members and carers to the area forum, as well as making suggestions for service improvement

and ensuring that issues are dealt with by local services, wherever possible. At the same time they will promote communication and information sharing.

### **Governance of local forums**

To help ensure good governance, every local forum will have terms of reference (which will define the purpose, objectives, membership and procedures of the group) and a code of practice (which will outline how members of the group are expected to work with each other to promote respect, non-discrimination and inclusion; how conflict and differences of opinion should be managed and how the views of members are to be represented).

A draft terms of reference and code of practice for local forums will be developed by the office of the head of Service User, Family Member and Carer Engagement and sent via area leads to area forums.

Local forums will need a chair, a secretary and someone to coordinate the activities of the forum.

The role of the chairperson is to ensure that the forum functions well, with full participation of all members and effective meetings in accordance with the terms of reference and code of practice.

The role of the secretary is to take the minutes of meetings, to keep a contacts list for all members and to support the chairperson in convening and running effective meetings.

The role of the coordinator is to support the chairperson and secretary in the on-going running of the forum. The coordinator should support the chair to ensure that the local

forums are supported to raise issues through the proper channels.

A coordinator may be a service user, a family member, a carer, a peer support worker or a HSE employee. Who is most suited to take on the role will depend on the circumstances in each area. If the coordinator is a HSE employee, he or she will not be a forum member but will be welcome to contribute to discussions at meetings.

### **Ethos and values of local forums**

The forum must be open, accountable, transparent and democratic (where possible) in terms of formal roles such as chair, and the appointment and selection of members to attend the area forum. It will be important to build trust and mutual understanding amongst the different interest groups.

### **Communication, accessibility and link to the area lead and forum**

The local forum should be accessible, open to all service users, family members and carers and its existence should be promoted within the local communities.

The area lead will need to build a relationship and communication channels with the local forums. They should regularly attend local forums and be in regular and frequent communication with the local forum chair and should return regular and updated information.

Minutes of local forum meetings should go to the area lead, and minutes of area forum meetings should go to the local forums.

<sup>1</sup> This is the current working job title.

## Area forum

There should be one area forum in each CHO. The area forum will be made up of service users, family members and carers, as well as statutory, voluntary and community-based service providers and groups. The reference group recommend that the meetings should take place at least every three months.

The area mental health management team should meet annually with the area forum in order to develop a collaborative partnership and ensure good quality communication.

### **Purpose of area forum**

The purpose of the area forum is to work collaboratively for improved mental health services across the CHO.

### **Terms of reference**

To capture, reflect on and communicate service user, family member and carer experience.

To advise service providers on local needs that impact on service provision and planning, and make recommendations for service improvement.

To be a mechanism for area mental health management to consult on proposed service development.

To provide a forum to enable communication and information which supports local forums.

To set up sub-groups (co-production groups, including additional external expertise when necessary) to work on designated task and to report back to the area forum as required.

### **Governance**

To help ensure good governance every area forum will adopt a terms of reference and a code of practice.

A draft terms of reference and code of practice for area forums will be developed by the office of the head of Service User, Family Member and Carer Engagement and sent via area leads to area forums.

The area lead should check that each area forum has terms of reference and a code of practice in place.

It is recommended that the area lead will chair the area forum to ensure that – through the forum – the views of service users, family members and carers can be represented at the area mental health management team and the MHD (through the head).

The area forum may need a large membership, however, so there should be a maximum of two members from each local forum attending. The area lead will decide, as chair, on the membership and quorum, in line with the agreed terms of reference.

The area forum, informed by the local forums and other mechanisms, should shape the work agenda for the area lead.

### **Ethos and values of the area forum**

The area forum should be recovery-oriented and solution-focused. It should ensure inclusion and equality for all those attending, including service users, family members, carers and service providers, and that all are treated with respect and dignity.

The area forum should aim to work on a collaborative, ‘trialogue’ basis –not in terms of ‘them and us’.

### **Communications and links**

There should be formal links to the local forums which can nominate one or two service users, family members and carers to the area forum. The forum must be of a size that allows it to function effectively. Minutes should be shared between the area and local forums. This will be covered in the terms of reference.

### **Support<sup>2</sup>**

The reference group strongly recommends that an administrative post at Grade III be assigned to the area leads. They will provide direct administration support to the area lead and the area forum, and in addition will assist with office systems and administration, including collating data received, managing contacts, communication with individuals and groups, linking local and area forums (including ensuring minutes are exchanged) and tracking issues raised at area forums.

This will be an ongoing need, as the forum is a key structure to support the role of the area lead and the engagement processes as outlined.

## Area lead of Service User, Family Member and Carer Engagement<sup>3</sup>

The reference group has developed a job specification for the role of area lead of Service User, Family Member and Carer Engagement, as specified below.

The main value that the area lead brings is ‘self, lived experience’ and recovery insight. This means that they have been directly affected by mental illness through personal experience and have developed an understanding of the recovery process needed to support good health. These values need to be held as important by the mental health services.

### **Grade<sup>4</sup>**

This position will be at Grade VII.

The Reference Group recommended Grade VIII because this ensured parity and equity with the Area Leads colleagues on the Area Mental Health Management Team. The National Management Team reached the decision that the Area Lead will be at Grade VII.

The reference group was of the view that the contents of the job specification and especially the principal duties and responsibilities are dependent on the post being at the senior management level of Grade VIII. In addition, the grade is commensurate with a senior manager in the HSE because to operate at a senior level in line with the job specification the person will need a very high level of skills, abilities and knowledge. It is also envisaged that the area lead may have to manage staff in time.

The reference group has developed a recommended job specification. The national management team reached the decision that this position will be at Grade VII. The Reference group were understanding of this decision.

<sup>2</sup> The current plan to secure GIII admin support is for the MHD to generate a bid in the 2016 service planning process to aim to secure resources for these posts.

<sup>3</sup> This is the current working job title.

<sup>4</sup> The Reference Group recommended Grade VIII because this ensured parity and equity with the Area Leads colleagues on the Area Mental Health Management Team. The National Management Team reached the decision that the Area Lead will be at Grade VII.

### **Direct line management and supervision structure**

While the CHO reorganisation is ongoing, the reference group cannot make a clear recommendation on who should take on these duties. It would seem reasonable to be the head of mental health or senior administrator for mental health services. Supervision arrangements should be in keeping with the arrangements for other members of the management team and not a clinician.

As there is no one to replace the area leads in their absence, unlike other members of the area management team they have no one that can 'act up' on a temporary basis to cover for leave. Therefore, if the area lead is on leave, particular issues that arise should be communicated or presented by members of the area forum to the area mental health management team. However, non-HSE personnel cannot be line managed by HSE staff and therefore this can only happen in an ad hoc way or on an informal basis. Another consideration would be to provide cover from an area lead from a neighbouring CHO.

This cross cover for the role may not be practical over any significant length of time. The reliance on the individual area leads should therefore be acknowledged as potentially problematic for the engagement processes.

This will be a new developmental role within the HSE and one which will present many challenges, including duality of role and competing demands from the management teams agenda and from a number of stakeholders. The availability of support is therefore important.

The reference group recommends that both a formal and informal support structure should be developed, as follows:

- Line manager and head of Service User, Family Member and Carer Engagement to provide regular support and supervision.
- Team building processes.
- Coaching and mentoring programmes within HSE.
- Externally facilitated group process for the area leads may be required, using a reflective practice approach. Whereby the area leads can use their experience to share with other area lead colleagues to develop their knowledge and expertise.
- Peer to peer or 'buddy' approaches whereby the area leads helps and supports other area leads working in other areas.

### **Role of the area lead**

The role should include community development approaches that allow for 'grass roots' feedback from the experiences, opinions and views of service users, family members and carers, as well as best available research-based information from Ireland and internationally, reflecting the most progressive thinking in developing modern mental health services from the perspective of SUFMC.

The reference group are agreed that one person will be able to represent the views of SUFMC and that a crucial aspect of the role will be to build trust and credibility amongst all stakeholders and ensure that he or she presents their views fairly. It is acknowledged that this may well be challenging.

### **Mandate**

The area lead should be prepared to bring meaningful and useful experiences from individuals into the area mental health management team, while being mindful of consent and confidentiality issues.

The area lead will develop local structures and mechanisms (as set out in this document) as well as current feedback systems such as *Your Service Your Say* (HSE mechanism to make a comment, compliment or complaint on HSE services) in place to give feedback on care planning and advocacy supports.

The area lead will need to be clear with all stakeholders about what their role is and that it is not advocacy nor is it directly involved in people's care plans. This also will need to be clear to candidates at all recruitment stages and especially at interview.

While some individual situations for service users, family members and carers will need the attention and support of the area lead, this may mean direct involvement in problem solving. Where at all possible individuals should be supported to use the service systems available. The area lead may be involved in monitoring the service response. At all times area leads should aim to ensure that the service users, family members and carers know how to take forward their own issues.

The mandate of the area lead will include the ability to be highly visible in the service to ensure that feedback is made available to them from SUFMC.

### **Recruitment and selection**

An implementation group is being established by the office of the head of

Service User, Family Member and Carer Engagement and, as part of this, will oversee recruitment and selection. This process will be completed in line with HSE recruitment policies with input from the HSE National Recruitment Service. All candidates for area lead posts must go through this process.

### **Location**

The base will be agreed at recruitment stage, in consultation with the area mental health management team, with consideration being given to the need for the post holder to be located in the administrative centre for the area mental health services.

The area lead will be expected to reach out to communities in their area and engage with all stakeholders, including the more vulnerable groups in the community. In order to be fully effective there should be access to meeting spaces as well as a level of committed administrative support.

The reference group recommends that administrative support at Grade III level be assigned to the area leads as noted under area forums earlier in this document.<sup>5</sup>

### **Additional mechanisms for engagement**

Every area should have a range of mechanisms for engaging with the wider population of SUFMC, including those who are unable to attend meetings.

Examples of such additional mechanisms would include listening meetings. The reference group recommends at least

<sup>5</sup> The current plan to secure GIII administration support is for the MHD to generate a bid in the 2016 service planning process to aim to secure resources for these posts.

one listening meeting per year in every area. Such meetings could be convened and facilitated by the area forum or by an external agency (such as a local voluntary organisation) with feedback to the area forum. The purpose of the meeting would be to hear the views and experiences of SUFMC. When the meeting is planned, consideration should be given to how to differentiate what are issues raised by service users, family members and carers from those raised by service providers. The listening meeting must be widely advertised and open to everyone in the area with an interest in mental health, including SUFMC, service providers and the general public. The area lead (with the area forum or other convening agency) will be responsible for collating the information from the listening meetings for a report which will inform mental health service planning at local and national level. The area lead will be responsible for ensuring that the area mental health management team review and respond to the issues raised in the report.

In addition, creative and responsive use of all type of communications media should be considered to facilitate consultation and engagement, for example:

- Leaflets.
- Information and communications technology (ICT) and social media.
- [www.yourmentalhealth.ie](http://www.yourmentalhealth.ie) and other websites.
- Smartphone Apps, such as Mind of My Own.
- Dropbox ([dropbox.com](http://dropbox.com)) an area or mechanism that people can link into regardless of time of day or whether a meeting is taking place.
- User-friendly directories of local services – both paper-based and online.
- Public meetings.

- Service user advocates.
- Peer support workers.
- Seminars and conferences.
- Postal or on-line surveys.

It is important to note that ‘word of mouth’ and personal recommendation from SUFMC will be vital for the promotion of engagement mechanisms.

#### **Information, data and research**

The national office, area leads and area forums will have a role in assisting with information and data collection. There should a focus on collaboration with voluntary or community organisations which are involved in research, as well as the Health Research Board (HRB) and third level institutions.

#### **Engagement with all groups**

The area forum and local forums should, over time, develop an emphasis on engaging and involving all relevant groups. Moreover, the following is a non-exhaustive list of some of those groups that require particular consideration.

- Young people—Child and Adolescent Mental Health Services (CAMHS) 0–18 and young adults 18–25).
- People with intellectual disabilities.
- Older people.
- People experiencing homelessness.
- Migrant groups.
- Ethnic minorities.
- Lesbian Gay, Bisexual and Transgender (LGBT).
- Prisoners.
- Forensic services.
- People with physical disabilities.
- People experiencing domestic violence or abuse.
- People in long-term acute units.
- People who struggle to engage with services.
- People with addictions.

#### **Remuneration and expenses**

The reference group is aware that the MHD is currently engaged in innovative work to develop procedures for remuneration in relation to Service User, Family Member and Carer Engagement. The reference group sees remuneration as a key enabler in the implementation of the recommendations. They recommend that the implementation plan should include a fair and transparent scheme that includes repayment for out-of-pocket expenses, such as travel and subsistence for attendance at local and area forums and national meetings remuneration for specific pieces of work in relation to Service User, Family Member and Carer Engagement in service improvement. Remuneration is also recommended for involvement in the design and delivery of training in relation to Service User, Family Member and Carer Engagement.

#### **Head of Service User, Family Member and Carer Engagement<sup>6</sup>**

The reference group developed a job specification for the role of head of Service User, Family Member and Carer Engagement.

The group recommended to the national management team that the grade would be at assistant national director level. The group feels strongly that this grade is required to reflect the division’s commitment to change. It is reflective of the authority required to be a direct assistant to the national director and it acknowledges the MHD’s clear commitment to collaboration at

<sup>6</sup> The National Management Team reached the decision that this position will be at a GM grade.

the highest level of decision-making. The role is to drive improvement and promote positive change as a member of the MHD and therefore there is a need to select someone who has exceptional skills and capabilities to deliver leadership at the highest level. The MHD reached the decision that this position will be at a GM grade. The reference group were understanding of this decision.

#### **Office of the Head of Service User, Family Member and Carer Engagement**

The purpose of the office is to support the head in the role of leading and implementing the development of structures, systems and mechanisms for Service User, Family Member and Carer Engagement, so that their views are central to the design and delivery of mental health services nationally and locally.

The work of the office will be under five key functions, which are:

- Advice, support and review in relation to the local structures for Service User Family Member and Carer Engagement.
- Information flow and data collection.
- Capacity building.
- Knowledge, expertise and research.
- Working with others to promote Service User, Family Members and Carers Engagement.

Actions to support these functions include:

- Advice, support and review in relation to the local structures for Service User Family Member and Carer Engagement.



- Provide support for the recruitment and selection of area leads of Service User, Family Member and Carer Engagement.
- Support and review the mechanisms and structures for SUFMC developed or sponsored by HSE.
- Co-ordinate the development, dissemination and review of terms of reference and codes of practice for local forums and area forums by working groups consisting of SUFMC and service providers.
- Provide guidelines on the make-up of local forums and area forums, in terms of the ratio of SUFMC membership and others.
- Provide guidelines and initial support for setting up area forums, local forums and other mechanisms for Service User, Family Member and Carer Engagement.
- Ensure that there are clear links with and representation of SUFMC on all service user forums developed in CHOs, including patient forums in acute hospitals.
- Develop Service User, Family Member and Carer Engagement in the planning and implementation of projects and service-improvement initiatives throughout the MHD.
- Develop accountability structures in relation to Service User, Family Member and Carer Engagement.

#### **Information flow and data collection**

- Establish systems and gather information on Service User, Family Member and Carer Engagement.
- Ensure that quality information from Service User, Family Member and Carer Engagement is influencing decision-making processes on an ongoing basis.
- Ensure there is a two-way flow of information between the Service User, Family Member and Carer Engagement and all relevant parties.
- Give assistance with and guidelines

for information and data collection at national, area and local levels.

#### **Capacity building**

- Support, promote and commission capacity building in relation to Service User, Family Member and Carer Engagement.
- Map what is currently available in terms of capacity building for Service User, Family Member and Carer Engagement.
- Provide training and capacity building guidelines in relation to both the area forums and local forums.
- Support the development of consistent, high quality training nationally in relation to the structures and mechanisms for Service User, Family Member and Carer Engagement.

#### **Knowledge, expertise and research**

- Develop knowledge and expertise in relation to Service User, Family Member and Carer Engagement, based on best practice and research both nationally and internationally.
- Lead and develop innovative practices and build an evidence base for Service User, Family Member and Carer Engagement.
- Share learning and knowledge across HSE divisions and other agencies.
- Work with others to promote to Service User, Family Members and Carers Engagement.
- Support and collaborate with other parts of the MHD to enable Service User, Family Member and Carer Engagement.
- Communicate and consult with national voluntary organisations in mental health to promote Service User, Family Member and Carer Engagement.
- Work with other stakeholders in relation to promoting Service User, Family Member and Carer Engagement in mental health services.

## **Strategic advisory group to the head of Service User, Family Member and Carer Engagement**

As a newly-created role within the MHD, the head of Service User, Family Member and Carer Engagement requires a support structure that will enable the organisation to function effectively.

#### **Purpose**

The purpose of the strategic advisory group is to support the head of SUFMC Engagement in the discharge of his or her role. The group will do this in the following ways:

Providing independent strategic and policy advice from a national and international perspective in relation to SUFMC Engagement in mental health services.

Providing a structure for the head of SUFMC Engagement to consult on the overall direction of engagement in mental health services, within the context of the vision and ideals of Service User, Family Member and Carer engagement, as espoused in *A Vision for Change*.

Providing external perspectives and ensuring fidelity to the grass roots experience of SUFMC Engagement.

A main function is to provide advice and consultation for the development phase of the role of the head and their office and should meet on a quarterly basis. It will consist of approximately six to eight members. The head of Service User, Family Member and Carer Engagement will convene and chair the group. The office should provide administrative support.

The head should establish the group in conjunction with the national director.

Membership of the group will be on the basis of an objective selection process. Members will have demonstrated ability to be involved in transformative leadership and will have wide and varied experience and knowledge in relation to SUFMC Engagement.

The recommended duration of the strategic advisory group is initially three years. The reference group is clear that the group membership must be renewed. The strategic advisory group's terms of reference should therefore reflect this and the group should be reviewed annually and evaluated after the first three years, and membership should change as part of this review.

#### **Key considerations in the development of both local and national engagement**

#### **Resources**

The reference group recommends that the necessary resources should be made available to fund all the structures and mechanisms recommended, including administration, facilitation, evaluation and reimbursement.

#### **Evaluation**

The structures and mechanisms for consultation and engagement will evolve over time and it will be important to regularly review and evaluate these at least once every three years.

Evaluation should focus on specific areas from which definite learning can be drawn to improve the engagement processes. This will be the role for the head and area leads.

**Accountability framework**

The reference group recommends that the overall Service User, Family Member and Carer Engagement structures should include accountability processes that measure the performance of the leads, area forums and local structures.

These should measure performance in two main areas.

One area is the need for accountability in ensuring that the structures are being developed and when in place are working—for example, that area forums are meeting as frequently as desired, and have received and are using the developed terms of reference.

The other area is the tracking of issues that are raised at the appropriate forums and ensuring feedback is returned to the local and area forums via the area lead and head. This will ensure that the mandate from the local and area forums is being fulfilled. For example, a report could be produced that notes what issues have been raised, how they have been escalated and responses received.

Other key performance indicators (KPIs) for the structures and groups, as well as for the reporting structure for feedback should be developed by the head and the office and these will form an annual accountability framework based on the prioritised actions for the office, head and the area leads.

The reference group is aware that during the first three years phase, the new structures and roles will be in a developmental phase and therefore recommends flexibility in relation to KPIs.

**Capacity building and training**

The reference group recommends investment in capacity building and training as a vital component of the work to establish, maintain and sustain structures and mechanisms for Service User Family Member and Carer Engagement. It is not possible for the reference group to endorse any one training method or model or any one particular training group. It recognises that there is already a number of training programmes available across the country. It does, however, recommend key areas that should be considered in the development of training and capacity building for different stakeholders.

Underpinning any training or capacity building initiative is a set of principles that should be a guide to the design, organisation and delivery of training in relation to the Service User, Family Member and Carer Engagement process.

The reference group has identified essential core modules for learning and development for:

- Members of local forums.
- Members of area forums.
- Area leads.

**Local forum: Learning and development needs**

Core modules recommended for training should include the following topics: fostering personal resilience through peer support, recovery, self-advocacy, community development, facilitation, meetings, presentation skills, sourcing, team building, working collaboratively, negotiation skills, conflict resolution and analysing information.

Policy context, HSE structures, local and national engagement structures, team building, leading change and working collaboratively.

**Area forum and area lead: Learning and development needs**

In addition to the local forum topics, core modules recommended for training should include the following topics: facilitation, networking, community development and partnership working. Policy context and HSE structures—with special attention to quality and service, user safety, service plans and operational plans, policy analysis and policy implementation. Role of local forums, area forums and national structures: Developing engagement structures.

**Guiding principles**

The reference group recommends the following principles to guide all capacity-building and training in relation to Service User, Family Member and Carer Engagement.

All training (where possible and appropriate) should be designed, organised and delivered through collaboration among SUFMC and service providers using the model and values of co-production. All training should be widely advertised, so as to ensure that the widest possible numbers of SUFMCs are given the opportunity to participate. Low income should not be a barrier to SUFMCs participating in training. Training should be provided to all local forums as part of the set-up process. Refresher training will be available to consumer forums that are already established. This training will be in line with the training programme outlined above, with the purpose of supporting local forums to work in an empowering, inclusive and effective way.

All members of local forums will be encouraged to avail of this training to enable them to contribute confidently and effectively.

Participants on training courses will be expected to make a commitment to put their learning into action through their involvement in the structures and mechanisms for Service User, Family Member and Carer Engagement. There should be training for SUFMCs who are moving on to an area forum for the first time.

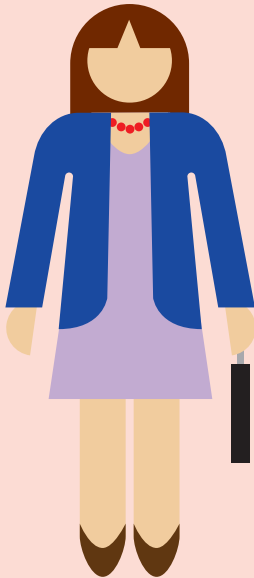
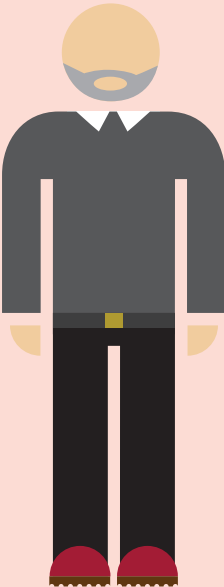
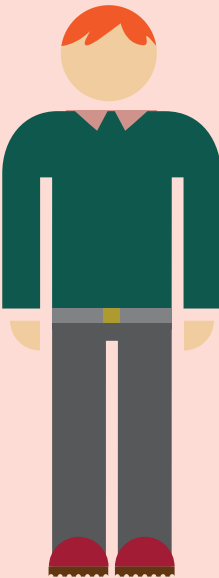
Area management teams will support, encourage and resource capacity building and training. In addition, area management teams will allocate bursaries to facilitate low income SUFMCs to avail of training opportunities, external to the HSE. Facilitation training for local forums should include looking at the developmental stages of SUFMC involvement. People often come in with feelings of anger, frustration and distress about services, but when heard, understood and acknowledged they can then proceed to work and make changes. Training for local forums needs to include how to contain and work constructively with strong emotions.

The office of the head of Service User Family Member and Carer Engagement also plays a key role in relation to capacity-building and training. This is achieved through supporting, promoting and commissioning capacity-building in relation to Service User, Family Member and Carer Engagement. At the same time the health delivery system maps what is currently available in terms of capacity-building for Service User, Family Member and Carer Engagement and provides training and capacity-building guidelines in relation to both the area forums and the local forums, while supporting the development of consistent, high quality training nationally in relation to the structures and mechanisms for Service User, Family Member and Carer Engagement.



# Chapter 3

## Reflections on the experience of building partnership for Service User, Family Member and Carer Engagement



*'One of the biggest challenges was that you had to let go of your own story. Many of us who lobby for a better mental health system are motivated by our own story. However, if we are to enter into a partnership that is designed to have equal membership for all, we must be willing to accept all aspects of this partnership. This sometimes means we don't get what we want or how we wanted it, but compromise is not loss, in fact it is the many little wins that eventually make big change, but for this to happen fairly for all, there must also be compromise'*

**REFERENCE GROUP MEMBER**

This chapter includes the reflections of both the independent chairperson and the reference group members on their experience of being part of the reference group.

### 3.1 Reflections of the independent chairperson

The office of the head of Service User, Family Member and Carer Engagement asked me, as independent chairperson, to reflect on my experience of working with the reference group with a view to identifying the learning that may be helpful for other similar groups, particularly the local and area forums due to be established in line with the reference group recommendations.

Putting meaningful structures and processes in place for the engagement of service users, family members and carers, requires tackling complex, multi-dimensional problems as well as a significant shift in power and in attitudes, behaviour and work practices amongst all stakeholders. There is important learning to be gleaned from the experience of the reference group for those who will be engaged in this change process either as service users, family

members and carers, staff members or managers. On the basis of thirty years facilitating partnership and collaboration in the community, voluntary and statutory sectors, I believe that the reference group was an excellent model of engagement, in terms of working collaboratively, creatively and inclusively to achieve the task within the required timeframe.

Towards the end of reference group everyone involved, service users, family members and carers, HSE staff and the MHD, had a shared sense of achievement and were excited about the prospects for real change in the way mental health services are planned, delivered and evaluated, as a result of the implementation of the recommendations. In addition the reference group members had developed their skills, knowledge and confidence as advocates for change, which will support their further contribution to the development of service user, family member and carer engagement. Overall it is clear to me that it was the development of partnership that distinguished the work of the reference group, that is partnership among service users, family members and carers, with the HSE staff and the MHD. Partnership requires shared vision and shared goals, determination to get the job done and commitment to doing it in a collaborative, mutually respectful way. It also requires a willingness to be self-reflective, flexible and open to change for the sake of making progress on shared goals. The experience of the reference group demonstrated that while building partnership is challenging, it is essential for progress in service user, family member and carer engagement and that it is ultimately rewarding for all involved. A combination of interdependent factors

helped develop partnership and I have grouped them here into six main areas:

### **3.1.1 Membership of the reference group**

### **3.1.2 Management leadership and commitment**

### **3.1.3 Terms of reference and work plan**

### **3.1.4 Supports**

### **3.1.5 Facilitation**

### **3.1.6 One voice**

## **3.1.1 Membership of the reference group**

A pivotal factor in the achievement of the reference group was that the members were service users, carers and family members who combined self-experience with many years of working for change in the delivery of health services as activists and advocates at local, regional and national levels. Members were selected through a transparent process. Many of the members had participated in educational courses related to service user engagement, either through voluntary and community organisations or educational institutions such as universities. The members drew on their invaluable learning and experience throughout the work of the reference group in planning an integrated national, area level and local structure for service user, family member and carer engagement.

## **3.1.2. Management leadership and commitment**

Another crucial factor in the effectiveness of this initiative was the role of the MHD in initiating, resourcing, and giving the reference group a mandate through the

terms of reference. The experience of the group highlights the importance of management leadership and commitment to the work of engagement structures. This includes ensuring that the structures receive the support they need, that there is an effective process for regular two-way communication between management and the structures and that there is meaningful engagement with and follow-up on the work.

As chairperson I was struck that trust was a central issue in the group, particularly trust in the intentions and commitment of the HSE. Members were concerned that the reference group would be 'another talking shop' and therefore a waste of their time and effort. This was no doubt due to previous experience of consultations with service users, family members and carers, which were seen not to have led to change. It was important that the national director came to meet the reference group at an early stage in their work and then again with the head of planning, performance and programme management at the final meeting. This showed the MHD's commitment to the process, helped two-way communication about the work of the reference group and ensured accountability. The MHD spoke to the area management teams about the work of the reference group, preparing them for the new roles and structures.

It was originally intended that the interim head for Service User, Family Member and Carer Engagement would be the liaison between the group and the MHD. In his absence the management team invited the reference group to nominate two representatives to meet with them on behalf of the reference group. The two representatives met the management

team twice; firstly to present and discuss the group's recommendations in relation to local structures and secondly in relation to the national structures. This direct communication was very important for building mutual understanding and trust. It gave the management team and the reference group representatives an opportunity to talk about the work of the group in greater detail, to share different viewpoints and to openly discuss reservations. It ensured that the MHD understood the rationale for the reference group recommendations and that the reference group understood the rationale for management team decisions in relation to the recommendations.

From the experience of the reference group it is clear to me that the leadership, commitment and support of the MHD, the area management teams and individual managers who act as champions for engagement, will be key to the successful implementation of the new roles and structures. They will need to:

- Provide leadership nationally and locally by highlighting and showing through their commitment that the development of structures for engagement is a priority for mental health services.
- Ensure that the development and on-going support of the new roles and structures is written into service plans.
- Give a clear mandate to the forums.
- Provide on-going support to the Forums, including resources.
- Ensure a process for accountability, and ensure that there is regular two-way communication.

### 3.1.3 Terms of reference and work plan

Having clear, concise realistic terms of reference was definitely one of the key factors that supported the work of the reference group. It gave the group crucial clarity on their common purpose, desired outcomes and timeframe and assisted me in my role as chairperson. We were able to refer back to them whenever a reminder was needed of what the group were there to do, what they needed to achieve and by when.

One of the first tasks of the group was to draw up a simple and timed work plan on the basis of the terms of reference. The project manager drew up a draft plan, which the group discussed, amended slightly and adopted. Having specific, measurable goals gave direction for action and helped measure achievements. It helped ensure that every meeting was focused on furthering the work plan and those discussions were purposeful and constructive.

The reference group members noted that an important factor was that they had time to work through the issues, to come back to contentious questions, to research material but that they also did not have too much time. However, the deadlines did put pressure on the group and led to tensions at times between members and the chairperson about when to continue discussions and when to move on with the task. I found it helpful to name these tensions and to ask the group to reflect on how we should deal with this understandable dilemma. Sometimes we decided to take more time, but generally the group were of the view that while it was frustrating not to be able to discuss some issues as much as they would like to, it was

important to stick to the deadlines which were useful in keeping them focused constructively on the task.

### 3.1.4 Supports and resources

The reference group experience indicates that for the new structures to work effectively it is essential that resources are made available for administration, facilitation, capacity building, evaluation, reimbursement and remuneration.

Reference group members highlighted that the reimbursement of out-of-pocket expenses and remuneration supported and enabled their participation. They also saw it as an indication that the MHD valued their experience, perspective and contribution.

The work of the reference group was also supported through the work of the project manager, the business manager and administrative support, who worked in partnership with the members. It was acknowledged that the group members and the HSE staff had different roles, different expertise and at times different perspectives, but they shared a strong commitment to the goals and to working collaboratively. As mutual trust and the sense of working as a team built with every meeting, so did flexibility, openness, and the ability to work constructively with differences. The members valued highly what the staff offered in terms of support, information, expertise, while both they and staff were clear that the staff role was not to make recommendations.

The project manager and the business manager provided invaluable leadership and support to the reference group. They provided leadership by ensuring that the group kept to their task in line with the

work plan, by highlighting difficulties when necessary, by affirming progress and providing encouragement and support to the group as a whole and to individual members. They provided back-up between meetings and followed up on tasks, writing up and disseminating minutes and other relevant materials. They facilitated the working-groups, encouraged and supported participation, clarified issues and looked externally for solutions to problems the reference group was encountering. They also liaised with other sections in the HSE. They were able to bring information about the HSE to the reference group, which helped the group's deliberations and decreased potential misunderstandings. When the reference group members were frustrated with delays or lack of responses from the HSE, the staff were able to give helpful perspective on the internal workings of the organisation. The HSE staff also supported me as the independent chair through regular joint reflection, reviews and planning.

### 3.1.5 Facilitation

On the basis of my experience as independent chair, I believe it is important not to underestimate the role of the facilitator in helping the group achieve its task, nor the skills and experience required to fulfil this role effectively. It is not easy to balance running the meetings efficiently and staying focused on tasks with ensuring that all members are encouraged to participate by giving enough space for individuals to express their views, and for the group to discuss ideas, concerns differences and potential conflicts. This was challenging for all of us at times, but the group understood the need to find this balance and invariably supported me in this role.

The reference group reflected the very real barriers to participation for service users, family members and carers, which include ill-health, low self-esteem and confidence, the impact of discrimination in their daily lives and having to deal with ongoing difficulties in relation to the level and type of service on offer to them personally or to someone for whom they are caring. These and other difficulties can lead to feelings of despondency, powerlessness, anger, frustration, anxiety, fear and hopelessness. It was inevitable that these feelings came into meetings at times. My role as chairperson required finding a balance between giving people time to express and acknowledge how these difficulties were affecting them and at the same time ensuring that the group stayed on track in dealing with its agenda.

One of the difficult issues for the group was how to deal with a member's absence due to sick leave. It is recommended that terms of reference make it clear that in the case of long-term sick leave, a member will not lose their membership but that the group can co-opt in their absence with a view to ensuring that the group has a quorum and sufficient representation.

Because of the trusting relationship that developed with the HSE staff, individual members were able to talk to them about difficulties or concerns in relation to their participation in the reference group. The support from the HSE staff, the mutual support among group members and the inclusive, respectful group atmosphere helped maintain the membership of the group.

Engagement structures such as the new area and local forums are not primarily for individual support and yet it is individual

experience that informs what service users, family members and carers bring to the groups, so it cannot be disregarded. The reference group discussed this dilemma, agreeing that it puts an onus on the chairperson or facilitator to get a workable and compassionate balance in allowing for personal expression when relevant to the work of the group and yet keeping a collective focus on the task at hand. The group recommended that the new structures consider how to ensure that there is support for people outside of the meetings and safe spaces for these emotions to be expressed and acknowledged. Having the opportunity to discuss and reflect on the impact of these difficulties helps people maintain the motivation to continue working for change.

Having highlighted some of the barriers to participation, I also want to highlight the strength, determination and vision of group members. Together they generated and maintained energy, commitment and enthusiasm for their complex task. They raised essential issues for discussion, attended to important details, engaged in robust discussion, highlighted progress when the group was discouraged and suggested new ways of looking at difficulties. The reference group was distinguished by the combined maturity, intelligence, compassion and sensitivity of the members, as well as their sense of humour and unfailing goodwill.

Many contentious issues were discussed in the group and members often had a divergence of views, both philosophical and practical, in relation to mental health and mental health services. As facilitator I aimed to allow time for engagement with these complex questions, while also making progress on the work plan at every meeting. It was important

from time to time when emotions were running high to remind the group of the need to maintain an atmosphere of mutual respect and to keep listening to each other even when that was difficult to do. The group members helped me with this by reminding each other of the ground rules and by pulling back from discussions that were not constructive or that while important were not immediately relevant to the task of the group. In this way the group worked in partnership with me and supported me in the role of facilitating the group.

Reference group members highlighted that taking a community development approach was key to the group's effectiveness. It was important that the group members, project manager, business manager and I, as chairperson, shared an understanding of and commitment to the principles of community development—that is participation, inclusion, collective focus, strengths focus and empowerment. The reference group stressed that it will be important that the new structures for service user, family member and carer engagement aim to reflect these principles in how they work.

In reviewing their experience members suggested that the team building could have started earlier, through, for example, having a meal together the night before the first meeting, so that the group could have begun to get to know each other informally at that stage. The group spoke about how getting to know each other personally did help them work more openly with each other in the group. They also emphasised the importance of induction for new members regarding structures for engagement, so that they could be supported to participate confidently as

soon as possible. Some members felt that it would have been better to have more time to fully discuss the different perspectives within the group on a number of important issues, such as what is meant by 'recovery', its implications in relation to service and individual decisions around the use of medication and the role of spirituality in recovery.

Over time it was clear that, through the sharing of personal experience and explaining the background to strongly held views, a greater understanding of the motivations, aspirations, needs and concerns of all group members was growing. This helped the work of the group in many ways, particularly in the development of what I have chosen to highlight as the sixth factor contributing to the development of the partnership—one voice.

### 3.1.6 One voice

Initially the reference group members felt that it would be necessary to have a different representative for service users and family members and carers because no one person could understand and validly represent both viewpoints. As the group worked together, listened to each other's experience and empathised with each other, they realised that they would be all the stronger if they could speak with one voice. They also realised that, because they had come to trust each other, one person from either sub-group could represent this group of service users, family members and carers as a whole. This was a very important turning point in planning the structures and for enlarging the reference group's vision for the service users, family members and carers' movement in the future.

In reviewing the work of the reference group the members stressed that they had learned from their own experience the importance of continually working to ensure that the service users, family members and carers develop and maintain a genuinely shared agenda and shared representation through the process of trust-building, empathy and listening to and teasing out different experiences. The group expressed the view that it will be important to work in a similar way in the local and area forums. Facilitating and supporting the development of trusting, collaborative relationships will require giving time and attention to both the task and process of the groups. Developing 'one voice' will not be easy and it may not always be possible.

Reference group members came to the view that in the context of effective and collaborative structures for engagement, the area leads will be able to present the views of service users, family members and carers regardless of their individual self-experience, as long as they are committed to listening to, understanding and including the experience and views of all three groups.

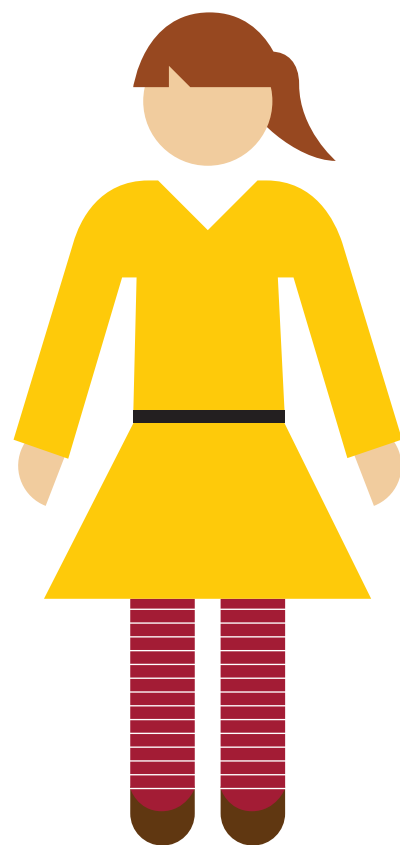
### 3.1.7 Summary

From my experience of working with the reference group, I would recommend that those involved in setting up or working within structures for Service User, Carer and Family Member Engagement try to ensure the following:

- That the group has the membership it needs to achieve its task.
- That there is management commitment to the work of the group and that



- there is a good process for regular communication with management.
- That there is adequate support in terms of remuneration for members' time and that the group has an experienced facilitator or that the facilitator has access to training and support.
- That the group is given a concise terms of reference, specifying the task of the group.
- That the group agrees a clear, timed work-plan on the basis of the terms of reference.
- That the group develops a code of practice, that is ground rules for how the group will work together with a particular emphasis on developing partnership and the principles of community development, including affording all involved the right to hold and voice their own views and to be treated with dignity and respect. Developing the code of practice requires discussing and agreeing how the group will deal with the inevitable differences, contentious issues and conflicts that will arise, while staying focused on the terms of reference and the work that needs to be done.



Finally, I wish to acknowledge that it is a source of pride to me to have been involved in the work of the reference group. I have no doubt that the recommendations will make a significant contribution to the development of service user, family member and carer engagement in mental health services. The reference group also has potential as a model for other areas in the health services where there is an interest in developing engagement.

## 3.2 Reflections of the reference group members

Four months after the end of the reference group, members were asked to reflect on their experience. This section collates direct quotes from their individual written responses. There is striking unanimity among the reflections, which serve to highlight the most important elements of the work from the perspective of the members.

*'It was unique in that although our views were radically different we were able to work together to try change the services.'*

*'Every member of the reference group brought something unique to the process, be it skills, experiences, education, knowledge, work rate, but ultimately a shared desire to involve SUFMC in the design and delivery of future mental health services.'*

### 3.2.1 How would you describe your experience of being a member of the reference group?

*'The day the letter came from the HSE to say I had been selected to represent service users on the reference group has to be one of the proudest moments in my life.'*

*'My experience on the reference group was very positive overall. The people who sat around the table to take on this piece of work exemplified the possibility that service users, family members, carers and service providers can work together in a way that each party feels heard and a goal can be reached that agreed by all.'*

### 3.2.2 Was the reference group different to your other experiences of service user, family member and carer engagement and if so how?

*'The reference group was different to my other experiences of service user, family member and carer engagement because it was the first time as a service user that my voice was on an equal footing with HSE representatives.'*

*'The year on the reference group was the first time I really felt that HSE Mental Health Division were genuinely interested and committed to engaging with, and listening to service users, family members and carers in a meaningful way.'*

*'It was a group setting of other carers and service users with a shared goal or aim. I was not the lone voice in the wilderness. The people around the table understood and shared some of my experiences. The professionals there were interested and they did not try to dominate or control.'*

*'The group was supported by Catherine (Project Manager) and Gerry (Business Manager) with their professional expertise and knowledge of the system. This was carried out in a patient, respectful way by both of them.'*

*'Having Jane as chair really enhanced the process. She respected and drove the group, getting the best from each member and she made sure that all voices were heard and helped the group to achieve tasks on time.'*

*'As time went on we developed into a capable, hard-working group where differences (and there were many) were heard and thrashed out. By the end of the group we all respected each other. We successfully achieved the goals of the group.'*

### 3.2.3 What did you find difficult or challenging?

*'Working on the reference group was a challenge because we had to put aside our personal agendas and work together as a cohesive group of people with vast and valuable experience of either being a service user or family member or carer.'*  
*'My early experience wasn't great, as soon after joining the reference group I became unwell and was in hospital. I was then informed that, because I missed a few meetings, I was no longer able to stay as part of the reference group. I found*

*this extremely frustrating, as it seemed to be against everything that the group was meant to be about. After a letter of complaint I was reinstated and my experience was better from then on. I have thoroughly enjoyed my time on the group and would recommend it to anyone.'*

*'The group was an open one and people did say what was on their minds. To me this was good, as this was a healthy recovery way of working. As a result of this there were sometimes heated discussions because of different opinions on topics. This was worked through by listening, discussing and learning from each other. I do think everyone had respect for each other and valued each other's contribution.'*

*'Yes, we had times when the discussion got heated and we discussed things like adults and these issues were resolved to the satisfaction of all. We were there to accomplish our tasks and we did this by leaving our own personal agendas at the meeting room door and we worked together in a forthright and fruitful manner to accomplish what we set out to do.'*

*'We had to remember that we were a team of people working together on an agreed set of tasks and that we had a limited amount of time to complete them. We did achieve this with cooperation and contribution from all.'*

### 3.2.4 Do you feel that your attitude or approach to service user family member and carer engagement changed from the start of the work to the end. If so, how?

*'As a service user I realised the importance of the voice of family members and carers. I also realised that the HSE is serious about service user, family member and carer engagement.'*

*'I think service users' attitudes changed in regard to family and carer issues; we became more aware of the challenges that families face and how much we all have in common.'*

*'The hardest thing we had to learn was that we no longer represented one group, either a service user or a carer, but we had to accept that we NOW represent and argue both sides of the debate.'*

*'Yes, my attitude changed because I had to accept that I was not only arguing for service users anymore but for family members and carers too, and putting their point of view across to management.'*

*'I would emphasise that learning will take place regardless of your initial intention, because by listening to others' opinions and experience you are going to learn something you may not have known before and all learning has to be good.'*

*'We learned a lot about the complexities of the HSE system and we also know more about the mental health advocacy services around Ireland and the consumer panels that exist.'*

### 3.2.5 What advice would you give to anyone starting a local or area forum?

- Identify a champion or champions in the HSE in each area who will be motivated to set up the new structures so that they will work.
- Find out what is already available in your area and visit other forums to see what works for them.
- Have a clear direction for the forum, clear terms of reference and a clear governance procedure, including guidelines for dealing with conflict.
- Give as many service users, family members and carers as possible the opportunity to participate in a local forum. Communicate and engage with people to encourage them to become involved.
- Have a good chairperson or co-ordinator to drive it and to make sure meetings are effective.
- It's important that both service users and family members and carers feel equally important and that one doesn't get more attention than the other. The group has to be able to trust one another, so allow plenty of time for the group to become familiar with each other. Support and encourage each other, as it is possible to work together. Do not engage in judgement but rather let people be heard and feel that they have been heard so that they can become more actively involved in advocating for and promoting change. Be honest, open, transparent and willing to share. Listen and be patient with each other. Most people at a forum have never had their grievances heard and are trying to change and improve things.



- Training for staff and service users, family members and carers is vital to allow a positive partnership to be fostered, including committee skills, facilitation skills and conflict resolution. Rotate the roles at the forum, panel or consumer group so that members are as multi-skilled as possible. Research your issues and topics to see what is happening locally and worldwide.
- Make sure that there are HSE supports in place, such as administration, and a system of adequate recompense for time and travel.
- Be realistic. You cannot change the system overnight.
- Finally, the HSE needs to be able to acknowledge the difficulties experienced by service users, family members and carers. They need to be able to say, 'I hear how terrible it has been for you.'



# Appendices

## Appendix 1

### Reference group terms of reference

The purpose of the Mental Health Service Users, Family Member and Carer Reference Group is: To deliberate and engage on issues of concern to service users, family members and carers in relation to the planning, design, delivery and evaluation of HSE mental health services. 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. To engage on measures to develop the capacity of service users, family members and carers to participate in the planning, design, delivery and evaluation of HSE mental health services.

### Objectives

In particular the reference group will: Make proposals to the Mental Health Division on the role of the head of Service User, Family Member and Carer Engagement and the appropriate structures and mechanisms to support this role. Make proposals to the Mental Health Division on the role of the service user, family member and carer representative on the MHD and the appropriate structures and mechanisms to support this role. Make proposals to the Mental Health Division on the training interventions required to support the national and

area level representative roles and training interventions required to support service users, family members and carers to participate effectively in consultative structures and mechanisms.

### Membership

Membership consists of eight service user representatives and four family and carer representatives, as follows:

Aaron Galbraith, Anne Foley, Anne Tiernan, Aoife Price, Bernadette Bushe, Brian Hartnett, Colette Nolan, Joan Higgins, John Kidney, Rory Doody, Maire Duffy and Michael Ryan.

### Chair

The reference group is chaired by Paddy McGowan, Interim Head of Service User Family Member and Carer Engagement, Mental Health Division HSE.

Where the chairperson is absent for an extended period the HSE Mental Health Division will nominate an independent person to assume the temporary role of chair.

Where a member of the group is absent due to illness for more than two consecutive meetings and cannot attend the third, his or her place may then be filled from the reference group panel. The absent member may rejoin the reference group when in a position to do so.

The reference group will be supported in its work by assigned Project Manager, Catherine O'Grady.

## Procedures

### Decision-making

Decisions will be made by consensus. Where a consensus cannot be achieved decisions will be made by vote. A two-thirds majority is required for a valid decision.

### Quorum

In order for meetings to go ahead and actions to be agreed, the minimum number of nine people should attend meetings.

### Working methods

The group has agreed to adopt a shared learning approach that involves group meetings, discussion papers and small group work where appropriate.

### Group meetings

A mental health service user family member and carer reference group will meet once a month on the first Wednesday of the month for a period of twelve months starting in September 2014.

### Minutes and agendas

Minutes will be taken and distributed by an appointed secretary. Agendas will be prepared by the chair with the assistance of the group project manager. Agenda items must be submitted to Catherine O Grady ten days prior to a scheduled meeting. Minutes will be distributed within one week following the meeting. Meeting papers will be circulated ten days in advance of meetings. Paper copies of all documents can be posted out to members and alternative formats can be provided, if requested. Meetings may include small group

discussions to share experiences and learning or to achieve specific tasks. Each item or issue on the agenda is given due process and due consideration but this is measured and prioritised according to its relevance to the work being undertaken by the reference group.

### Subgroups

There may be occasions to undertake subgroup meetings to complete a specific piece of work. Where members are unable to work remotely, remuneration for subgroup meetings is limited to two hours maximum per month. Reference group members can only be involved in one subgroup at a time, unless otherwise instructed by the chairperson.

### Sharing of information and resources (including confidential materials)

Through group meetings and electronic communications members will be able to share information and resources. It is each member's responsibility to make it clear where a matter should remain confidential and not for discussion outside the group.

When sharing documents, members should make it clear if there is a restriction as to:

- Circulation of the documents beyond the group.
- Copyright or use of the contents.
- At the end of each meeting, the group will review, in consultation with all members of the group what matters or items are to remain confidential – that is for member's information only.
- Members of the group must identify issues of confidentiality brought to the group.

- As a reference group established by the HSE the deliberations of the reference group will be subject to the requirements of Freedom of Information legislation.

### Review

The group will review the relevance and value of its work and the terms of reference on four monthly intervals. The next review is due in February 2014.

## Appendix 2

### Reference group biographies

#### Aaron Galbraith

Aaron is a family member who has also had personal experience of mental distress. He works in the homeless sector, in particular with people that are homeless due to chronic mental distress and or those with problems of addiction. Aaron works as a volunteer as part of the Youth Empowerment Service (YES) which is a youth-lead advocacy service for young people who are inpatients in Willowgrove Adolescent Unit, St. Patrick's Mental Health Service.

#### Anne Foley

Anne is a service user for sixteen years and a chairperson of Wexford and Waterford consumer panel for mental health. She founded her local peer support group A Better Tomorrow for people who have issues with their mental health and who require peer support. Anne is a member of a local Advancing Recovery Ireland Group.

#### Anne Tiernan

Anne is a family member. Her daughter has been linked with the mental health services for the past six years. She

has been on the Dublin South Central Advancing Recovery Ireland Steering Group and Recovery College Steering Group. She is currently co-facilitating a family education/recovery course with Shine, the national organisation dedicated to campaigning for the rights and empowerment of all people affected by mental ill health.

#### Aoife Price

Aoife has served on Headstrong's Youth Advisory Panel for the past four years. She is passionate about youth participation and involving young people in the development of services. Aoife developed SPARKS a book, exhibition and animation that provides empathy and hope to those experiencing a difficult time in their lives.

#### Bernie Bushe

Bernie is a carer family member who is involved in Trialogue (Triologue is a space where an open conversation about mental health between professionals, carers and service users takes place) for the last four years. She is a facilitator in a Hearing Voices community group based in Dublin city centre. Bernie is a strong believer in human rights and feels that our mental health services are too controlling and are not listening enough to the concerns of service users or family members.

#### Brian Hartnett

Brian has personal experience of mental health difficulties. His first job in the area of mental health was with the Irish Advocacy Network as a peer advocate. He founded Hearing Voices Ireland (HVI) in 2006 to promote and foster acceptance of voice hearing as a valid human experience. He also lectures in third level institutions about personal experience and on his mental health work.

**Colette Nolan**

Colette has experienced mental health difficulties and has worked in the field of service user representation for the past fifteen years. She works with the Irish Advocacy Network, which is a service user, service-run organisation and is a board member of the Mental Health Commission, Mental Health Reform and Threshold Training Network.

**Joan Higgins**

Joan is a family member and carer. She is a member of the Mayo consumer panel. Joan was part of a group that campaigned for family friendly mental health services with Shine. She co-facilitates the Shine family and recovery course. Joan is involved in a voluntary capacity in various groups, steering groups, advisory groups and projects, both locally and nationally with the HSE. Recently she has started working as a Behaviour Family Therapy (BTF) facilitator with the Bealach Nua project, which is funded by Genio.

**John Kidney**

John has had personal experience of mental health difficulties. He has been active in the service user movement for the past ten years. John assumed the role of service user representative on the expert group advising Minister Kathleen Lynch on changes to the Mental Health Act (2001). He is currently a service user representative on Recovery, Experience, Forum of Carers and Users of the Service (REFOCUS) which advises the College of Psychiatrist of Ireland (CPI) on family and service user issues.

**Madge Fogarty**

Madge has had personal service user experience. She set up a support group to support women and their families through postnatal depression twenty-

three years ago and is therefore now a carer and supporter. She runs a voluntary group, partly funded by the HSE, which runs support groups and gives talks in antenatal classes in Cork University Maternity Hospital. The support group provides a helpline and has its own website and Facebook page. Madge co-wrote a book on postnatal depression in Ireland called Recovering from Postnatal Depression.

**Maire Duffy**

Marie is a service user and has an interest in service user involvement, with a particular interest in youth mental health. She has been an adviser to Headstrong (The National Centre for Youth Mental Health, which is a charitable organisation supporting young people’s mental health in Ireland) in the past and was part of a working group that helped bring Jigsaw (a network of programmes across Ireland designed to make sure every young person has somewhere to turn to and someone to talk to) to Letterkenny, Donegal. Marie is also a mental health blogger and has a strong interest in using social media to promote mental wellbeing.

**Michael Ryan**

Michael has personal mental health and service user experience. He has an educational background and has been involved in promoting recovery and working with marginalised groups for a number of years. He is currently employed as a peer lead on the Advancing Recovery in Ireland (ARI) project. This project aims to identify ways in which recovery principles can best be incorporated into routine practice in our mental health services.

**Rory Doody**

Rory has had over twenty years service user experience and has worked within the mental health services since 2009. Currently his work as a ‘Recovery Development Advocate’ involves working locally, regionally and nationally with service development and management, such as Hearing Voices Steering Group, ARI , Peer Support, and ARI Service Audit Committee. He works as a lecturer and course co-ordinator in

University College Cork. Concurrently Rory manages his caseload with the Home Focus Team HSE and the National Learning Network (National Learning Network provides a range of flexible training programmes and support services for people who need specialist support (job seekers, unemployed, people with an illness or disability) in 50 centres around the country. He is also a board member of Sli Eile.

## Appendix 3

### Draft Job Specification<sup>7</sup>: Head of Service User, Family Member and Carer Engagement, National Mental Health Division

<b>Job Title and Grade</b>	Head of Service User, Family Member and Carer Engagement, National Mental Health Division.  Grade – General Manager.
<b>Competition reference</b>	To be completed by NRS.
<b>Closing Date</b>	To be completed by NRS.
<b>Proposed interview date(s)</b>	NRS will insert proposed date of interviews.
<b>Taking up Appointment</b>	The start date will be indicated at job offer stage.
<b>Location of Post</b>	Head of Service User, Family Member and Carer Engagement will be assigned the National Division and will be line managed by the National Director of MHD.
<b>Organisational Area</b>	Mental Health Division.

<sup>7</sup> The reference group recommended that this position be an assistant national director. The MHD reached the decision that this position will be at General Manager grade.

**Details of Service**

Health care services in Ireland are undertaking a significant reform programme in line with Government policy as outlined in its strategy “Future Health—A Strategic Framework for the Reform of the Health Service 2012–2015.

The “Community Healthcare Organisations” report was commissioned by the HSE in May 2013, to review Community Healthcare services.

This report provides a framework for the governance and organisation of all of Community Healthcare services. The recommendations from these Reports provide for a new way of working for the most important part of our health services—the operational delivery system that provides health and personal social care services to the population of Ireland.

Community Healthcare Services are the broad range of services that include Primary Care, Social Inclusion, Social Care, Mental Health and Health and Wellbeing Services. These services are delivered through the HSE and its funded agencies to people in local communities, as close as possible to people’s homes. Full details of the services provided by a CHO can be found at [www.hse.ie/eng/services/publications/corporate/CHORreport.html](http://www.hse.ie/eng/services/publications/corporate/CHORreport.html)

The Mental Health Division has operational and financial authority and accountability for all mental health services, extending from promoting positive mental health through to suicide prevention and supporting those experiencing severe and disabling mental illness. It includes specialised secondary care services for children and adolescents, adults, older persons and those with an intellectual disability and a mental illness. Full details can be found at [www.hse.ie/eng/services/list/4/Mental\\_Health\\_Services](http://www.hse.ie/eng/services/list/4/Mental_Health_Services)

*The Report of the Expert Group on Mental Health Policy—A Vision for Change (2006)* is a progressive, evidence-based document, which proposed a new model of service delivery, which would be patient-centred, flexible, and community based. *A Vision for Change* remains the current roadmap, charting the way forward for the Mental Health Service.

This post is developed in line with *A Vision for Change’s* stated aim to: *involve service users and their families and carers at every level of service provision* (p.8).

**Details of Service (continued)**

The post holder will be a member of the Mental Health National Management Team (MHNMT) which in summary is charged with:

- Managing safe delivery of mental health services on a day to day basis
- Driving continuous service quality improvement in line with Vision for Change
- Leading the Mental Health Services through the full implementation of the Governments Healthcare reform programme.

To be successful the MHNMT will need to:

- Model the future behaviour and culture required in our mental health services including the full involvement of service users and family / carers in the design and operation of recovery focused services
- Create the conditions necessary to enable those working in mental health to fulfill their potential, to feel they are valued and to take full ownership of their responsibilities to Service Users, Family Members and Carers
- Create the clinical and managerial capacity to deliver safe, high quality services which are cost effective and can transition safely to the provider model i.e. within autonomous local community trusts as part of the overall health reform programme involving Universal Health Insurance and the move to money follows the patient for relevant services
- Design and implement world class models of mental health promotion and models of recovery focused mental health care in keeping with A Vision for Change and utilising the national clinical programmes
- Remove inappropriate variation in mental health service provision including in how services users access the service particularly out of hours
- Adopt a well structured approach to designing, incentivising and measuring integration within mental health services and between mental health and other services (health, social care and other public services)
- Develop and implement a performance management culture within our mental health services
- Maximise the benefits to service users and their carers of the ongoing government investment in the Mental Health Services

<p><b>Details of Service (continued)</b></p>	<ul style="list-style-type: none"> <li>• Cultivate sustainable positive relationships with key internal and external stakeholders. This includes service user and family / carer organisations, government departments, state agencies, NGO partners and funded organisations, public representatives, media, professional and training bodies, trade unions, MHC, HSE service divisions (Primary Care, Acute Hospitals, Social Care and Wellness) and HSE functions</li> <li>• Foster sustainable practical models for individual volunteerism and community involvement in promoting positive mental health and supporting service delivery</li> <li>• Build the capacity to demonstrate with evidence that they have delivered on the critical success factors above.</li> </ul>
<p><b>Reporting Relationship</b></p>	<p>The Head of Service User, Family Member and Carer Engagement will report directly to the National Director.</p>
<p><b>Key Working Relationships</b></p>	<p>The Head of Service User, Family Member and Carer Engagement will develop effective working relationships with the:</p> <p>National Director MHD</p> <ul style="list-style-type: none"> <li>— All other members of the National MHD Management Team</li> <li>— Other National Leads in the HSE</li> <li>— Area Leads of Service User, Family and Carer Engagement</li> <li>— Service Users, Families and Carers</li> <li>— Service providers, including national voluntary and community organisations.</li> </ul>
<p><b>Purpose of the Post</b></p>	<p>In line with <i>A Vision for Change</i> the purpose of this post is to provide focused leadership within the National Mental Health Division in relation to:</p> <ul style="list-style-type: none"> <li>— Consulting with and presenting the views of Service Users, Family Members and Carers</li> <li>— Engagement and partnership processes with all relevant stakeholders including Mental Health Services and</li> <li>— Participating, informing and influencing decision making at National Mental Health Management level.</li> </ul>

<p><b>Principal Duties and Responsibilities</b></p>	<ul style="list-style-type: none"> <li>• To lead the development of engagement structures, systems and mechanisms to ensure that the views of Service Users, Family Members and Carers are central to the design and delivery of mental health services</li> <li>• To work as an effective team member within the National Mental Health Management Team including participating effectively in National Mental Health Services decision-making processes</li> <li>• To lead the development of the Office of the Head of Service User, Family Member and Carer Engagement within the Mental Health Division</li> <li>• To contribute to the development of Strategic and Operational Plans within the National Mental Health Division</li> <li>• To drive improvement and positive change in the experience of Service Users, Family Members and Carers and support quality, safety and service improvement agendas from a recovery perspective</li> <li>• To work collaboratively with Area Leads and other colleagues to drive the agenda for Service User, Family Member and Carer engagement</li> <li>• To develop the team working agenda to promote coordination, communication, information sharing and mutual support amongst the Head and Area Leads</li> <li>• To review and plan for the role of the Area Leads in line with the national priorities for Service User, Family Member and Carer Engagement</li> <li>• To present the feedback from the Area Leads, and associated structures and mechanisms, at the national level and return regular and updated information to Service Users, Family Members and Carers</li> <li>• To perform roles, responsibilities and duties in accordance with the HSE and MHD Policies, Procedures and Strategic and Operational plans</li> <li>• To utilise opportunities to gather the views of those Service Users, Family Members and Carers that are underrepresented, additionally vulnerable or voiceless and ensure that those views are also central to the design and delivery of mental health services</li> <li>• To negotiate for the best use of resources to deliver maximum benefit to Service Users, Family Members and Carers in line with HSE and MHD Policies, Procedures and Strategic and Operational plans</li> </ul>
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<p><b>Principal Duties and Responsibilities</b> (continued)</p>	<ul style="list-style-type: none"> <li>To have contact with Service Users, Family Members and Carers both at group and individual levels and to respond appropriately including delegation to Area Lead and other services as required</li> <li>To inform, influence and support other members of the National Mental Health Management Team in carrying out their duties with the benefit of up to date, practical Service User, Family Member and Carer input, which is, where possible, evidence-based or evidence-led from a recovery perspective</li> <li>To manage the Office of Service User, Family Member and Carer Engagement, to ensure fulfilment of its functions, (ensuring compliance with data protection legislation) including:             <ul style="list-style-type: none"> <li>To support and advocate for regular auditing by services of Service User, Family Member and Carer experience and satisfaction.</li> <li>To gather data and information on engagement within mental Health Services</li> <li>To prepare reports as required by the National Director</li> <li>To publicise training events for Service Users, Family Members and Carers</li> <li>To monitor, record and provide governance for the payment of expenses and remunerations in line with HSE Financial Governance Arrangements</li> <li>To plan and monitor expenditure to ensure that the office remains within its budget.</li> </ul> </li> </ul> <p>The above Job Description is not intended to be a comprehensive list of all duties involved and consequently, the post holder may be required to perform other duties as appropriate to the post, which may be assigned to him/her from time to time, and to contribute to the development of the post while in office.</p>
<p><b>Eligibility Criteria Qualifications and / or experience</b></p>	<p><b>The successful candidate must demonstrate:</b></p> <ul style="list-style-type: none"> <li>Personal experience of mental health difficulties or Family Member/Carer experience of caring for a person with mental health difficulties</li> <li>A strong track record and demonstrable competence in the support and development of projects and new initiatives that promote positive and recovery focussed mental health</li> <li>Relevant experience, across one or more roles, of highly effective leadership and management which may have included a mental health services component</li> </ul>

<p><b>Eligibility Criteria Qualifications and / or experience</b> (continued)</p>	<ul style="list-style-type: none"> <li>Awareness and understanding of the challenges and opportunities of the mental health arena, including knowledge of current best practice and critical analysis of different approaches</li> <li>Strong record of playing a lead role in delivering change in a complex environment including significant experience in cultural change and driving an ethos of customer service</li> <li>Awareness and understanding of financial governance and management systems.</li> </ul> <p><b>Health</b> A candidate for and any person holding the office must be fully competent and capable of undertaking the duties attached to the office and be in a state of health such as would indicate a reasonable prospect of ability to render regular and efficient service.</p> <p><b>Character</b> Each candidate for and any person holding the office must be of good character</p> <p><b>Age</b> Age restrictions shall only apply to a candidate where he/she is not classified as a new entrant (within the meaning of the Public Service Superannuation Act, 2004). A candidate who is not classified as a new entrant must be under 65 years of age.</p>
<p><b>Skills, competencies and / or knowledge</b></p>	<p><b>Knowledge / aptitude—Demonstrate:</b></p> <ul style="list-style-type: none"> <li>A strong understanding of recovery principles and a recovery-oriented ethos</li> <li>In depth knowledge of mental health services</li> <li>An ability to provide creative and innovative approaches to current Mental Health practices and an awareness of current best practices in other jurisdictions</li> <li>Particular strengths in gathering, assimilating, organising and especially communicating significant volumes of complex information, including reports, in the context of decision making processes informed by Service User, Family Member and Carer feedback</li> <li>A working knowledge of and competence in use of Word, Excel and Email.</li> </ul>



**Skills, competencies and / or knowledge**  
(continued)

**Critical Analysis and Decision Making—Demonstrate:**

- Knowledge of and application of evidence based decision making practices and methodologies
- Strong ability to evaluate complex information from a variety of sources and make effective decisions
- Highly effective problem solving
- Well developed skills and a strong ability to challenge effectively and to maintain the highest levels of professional integrity in challenging circumstances.

**Planning and Organising—Demonstrate:**

- Outstanding organisational and time management skills to meet objectives within agreed timeframes and achieve quality results
- Excellence in effective planning and organisational skills including an awareness of resource management and the importance of value for money
- Strong ability to improve efficiency within the working environment and the ability to evolve and adapt to a rapidly changing environment
- The ability to work to tight deadlines and operate effectively with multiple competing priorities
- The capacity to operate to a high standard in a challenging operational environment while adhering to quality standards.

**Leadership and Direction—Demonstrate:**

- Evidence of excellence in personal and career development
- A strong knowledge and an ability to communicate current national mental health policy, as well as best practice and forward thinking in the area of Service User, Family Member and Carer engagement
- Detailed knowledge of mental health services and the service planning process
- Knowledge of the bio-psychosocial model
- Knowledge of and expertise in community development
- Progressive, innovative and creative approaches in responding to challenges
- The capacity and personal resilience skills to operate effectively in a leadership role

**Skills, competencies and / or knowledge**  
(continued)

- Excellence in the capacity to lead, organise and motivate people to function effectively in times of rapid change
- A robust results focus and ability to achieve through collaborative working.

**Teamwork, working with and through others—Demonstrate:**

- Excellent communication, interpersonal and networking skills including group facilitation, presentation and especially team working skills
- An ability to support, develop and empower people in a challenging environment and within existing resources
- Excellent leadership skills
- A track record of building and maintaining key internal and external relationships in furtherance of organisational goals.
- A core belief in and passion for the sustainable delivery of high quality service user focused services
- An ability to influence and negotiate effectively in furthering the objectives of the role
- A strong ability to be empathetic to others with different experiences and objectively represent the views of others fairly, accurately and objectively as required.

**Personal Commitment and Motivation—Demonstrate:**

- A value system compatible with the aims and ethos of the HSE and the vision and mission of the National Mental Health Division
- A strong commitment to continuing professional development
- A deep commitment to and ability to lead on improving recovery outcomes for people who use Mental Health services
- Clear capacity to cope with competing demands without a diminution in performance.

The National Head of Service User, Family Member and Carer Engagement will be required to supervise and line manage the staff of the Office of the Head of Service User, Family Member and Carer Engagement. In addition, the role will involve supportive and development functions with the Area Leads of Service User, Family Member and Carer Engagement.

<b>Other requirements specific to the post</b>	Access to transport as post will involve frequent travel.
<b>Competition Specific Selection Process</b>	<p>Short listing may be carried out on the basis of information supplied in your application form. The criteria for short listing are based on the requirements of the post as outlined in the eligibility criteria and skills, competencies and/or knowledge section of this job specification. Therefore, it is very important that you think about your experience in light of those requirements.</p> <p>Failure to include information regarding these requirements may result in you not being called forward to the next stage of the selection process.</p>
<b>Short listing/ Interview</b>	Those successful at the short listing stage of this process (where applied) will be called forward to interview.
<b>Code of Practice</b>	<p>The Health Service Executive will run this campaign in compliance with the Code of Practice prepared by the Commission for Public Service Appointments (CPSA). The Code of Practice sets out how the core principles of probity, merit, equity and fairness might be applied on a principle basis. The Codes also specifies the responsibilities placed on candidates, feedback facilities for candidates on matters relating to their application, when requested, and outlines procedures in relation to requests for a review of the recruitment and selection process, and review in relation to allegations of a breach of the Code of Practice. Additional information on the HSE’s review process is available in the document posted with each vacancy entitled “Code Of Practice, Information For Candidates”.</p> <p>Codes of Practice are published by the CPSA and are available on <a href="http://www.hse.ie">www.hse.ie</a> in the document posted with each vacancy entitled “Code of Practice, Information For Candidates” or on <a href="http://www.cpsa-online.ie">www.cpsa-online.ie</a>.</p>

The reform programme outlined for the Health Services may impact on this role and as structures change the job description may be reviewed.

This job description is a guide to the general range of duties assigned to the post holder. It is intended to be neither definitive nor restrictive and is subject to periodic review with the employee concerned.

## Appendix 4

### Draft Job Specification: Area Lead of Service User, Family Member and Carer Engagement <sup>8 9</sup>

<b>Job Title and Grade</b>	<p>Area Lead of Service User, Family Member and Carer Engagement.</p> <p>Grade VII</p>
<b>Competition reference</b>	To be completed by NRS
<b>Closing Date</b>	To be completed by NRS
<b>Proposed interview date(s)</b>	NRS will insert proposed date of interviews
<b>Taking up Appointment</b>	The start date will be indicated at job offer stage
<b>Location of Post</b>	<p>Area Lead of Service User, Family Member and Carer Engagement will be assigned 1 to each CHO Area and to the following locations: (TBC).</p> <p>NB—the posts should be located in the main administrative base for the MHS per CHO.</p>
<b>Organisational Area</b>	Mental Health Division
<b>Details of Service</b>	<p>Health care services in Ireland are undertaking a significant reform programme in line with Government policy as outlined in its strategy “Future Health—A Strategic Framework for the Reform of the Health Service 2012–2015</p> <p>The “Community Healthcare Organisations” report was commissioned by the HSE in May 2013, to review Community Healthcare services. This report provides a framework for the governance and organisation of all of Community Healthcare services. The recommendations from these Reports provide for a new way of working for the most important part of our health services—the operational delivery system that provides health and personal social care services to the population of Ireland.</p>

<sup>8</sup> This is the current working job title.

<sup>9</sup> The National Management Team reached the decision that this position will be at Grade VII.

<p><b>Details of Service</b> (continued)</p>	<p>Community Healthcare Services are the broad range of services that include Primary Care, Social Inclusion, Social Care, Mental Health and Health &amp; Wellbeing Services. These services are delivered through the HSE and its funded agencies to people in local communities, as close as possible to people’s homes. Full details of the services provided by a CHO can be found at <a href="http://www.hse.ie/eng/services/publications/corporate/CHORreport.html">www.hse.ie/eng/services/publications/corporate/CHORreport.html</a></p> <p>The Mental Health Division has operational and financial authority and accountability for all mental health services, extending from promoting positive mental health through to suicide prevention and supporting those experiencing severe and disabling mental illness. It includes specialised secondary care services for children and adolescents, adults, older persons and those with an intellectual disability and a mental illness. Full details can be found at <a href="http://www.hse.ie/eng/services/list/4/Mental_Health_Services">www.hse.ie/eng/services/list/4/Mental_Health_Services</a></p> <p><i>The Report of the Expert Group on Mental Health Policy - A Vision for Change (2006)</i> is a progressive, evidence based document which proposed a new model of service delivery which would be patient-centred, flexible and community based. <i>A Vision for Change</i> remains the current roadmap, charting the way forward for the Mental Health Service.</p> <p>This post is developed in line with <i>A Vision for Change’s</i> stated aim to: involve service users and their families and carers at every level of service provision.</p>
<p><b>Reporting Relationship</b></p>	<p>The Area Lead of Service User, Family Member and Carer Engagement will report directly to the Community Health Organisation, Head of Mental Health/Senior Administrator, to which the post holder is assigned.</p>
<p><b>Key Working Relationships</b></p>	<p>The Area Lead of Service User, Family Member and Carer Engagement will develop effective working relationships with the following:</p> <ul style="list-style-type: none"> <li>• Head/Senior Administrator of Mental Health Services in the CHO.</li> <li>• Head of Service User, Family and Carer Engagement.</li> <li>• Other members Area Mental Health Management Team.</li> <li>• Service Users, Families and Carers.</li> <li>• Service Providers Voluntary and Community Organisations.</li> </ul>

<p><b>Purpose of the Post</b></p>	<p>In line with <i>A Vision for Change</i> the purpose of this post is to consult and present the views of Service Users, Family Members and Carers through engagement and partnership with all relevant stakeholders including Mental Health Services and to influence decision making at Area Management level.</p>
<p><b>Principal Duties and Responsibilities</b></p>	<ul style="list-style-type: none"> <li>• To present the views of Service Users, Family Members and Carers in mental health services, including (a) being a full and proactive member of the Area Management Team for Mental Health Services, and (b) participating effectively in all related processes.</li> <li>• To implement the development of structures that allow for the involvement of Service Users, Family Members and Carers in the planning, design, implementation and evaluation of mental health services</li> <li>• To present the feedback from the Area Forum, and associated structures and mechanisms, at the Area Mental Health Management level and return regular and updated information to Service Users, Family Members and Carers</li> <li>• To identify and highlight the mental health needs of the most vulnerable groups who are using or need support from secondary and tertiary mental health services</li> <li>• To perform roles, responsibilities and duties in accordance with the HSE and MHD Policies, Procedures and Strategic and Operational Plans</li> <li>• To participate in Area Mental Health Services decision-making processes on issues directly affecting Service Users, Family Members and Carers</li> <li>• To promote and support the implementation of recovery-oriented services</li> <li>• To engage directly with service providers, (statutory, voluntary &amp; community), to ensure they understand what Service Users, Family Members and Carers require</li> <li>• To drive the establishment of a culture of involvement for Service Users, Family Members and Carers in the planning, design, implementation and evaluation of mental health services</li> <li>• To negotiate for the best use of resources to deliver maximum benefit to Service Users, Family Members &amp; Carers in line with HSE and Mental Health Division Policies, Procedures, Strategic and Operational Plans</li> <li>• To have contact with Service Users, Family Members and Carers both at group and individual levels</li> </ul>

<p><b>Principal Duties and Responsibilities</b> (continued)</p>	<ul style="list-style-type: none"> <li>To ensure at all times that the views of Service Users, Family Members and Carers are central to the management of the services</li> <li>To ensure the above requirement is fulfilled through active participation in the management of the Area Mental Health Service</li> <li>To advise, influence and support each member of the Area Mental Health Management Team in carrying out their duties with the benefit of creative, innovative and where possible evidence based or evidence led, up to date and practical Service Users, Family Members and Carers input from a recovery perspective</li> <li>To set up and manage information and administration systems to allow best available information to support this role, ensuring compliance with data protection legislation. This may include:             <ul style="list-style-type: none"> <li>To collect information about Service User, Family Member and Carer involvement</li> <li>To establish and maintain a database for the Office</li> <li>To prepare reports to management about Service Users, Family Members &amp; Carers involvement as in so far as possible</li> <li>To publicise training events for Service Users, Family Members &amp; Carers</li> <li>To monitor, record and provide local governance for the payment of expenses and remunerations in line with HSE Financial Governance Arrangements</li> <li>To plan and monitor expenditure to ensure that the office remains within its budget</li> <li>To regularly evaluate Service User, Family Member and Carer satisfaction.</li> </ul> </li> </ul>
<p><b>Eligibility Criteria Qualifications and / or experience</b></p>	<p>The successful candidate must demonstrate:</p> <ul style="list-style-type: none"> <li>Personal experience of mental health difficulties or Family Member/Carer experience of caring for a person with mental health difficulties</li> <li>Awareness and understanding of the challenges and opportunities of the mental health arena, including knowledge of current best practice and critical analysis of different approaches</li> <li>A track record and demonstrable competence in the support and development of projects and new initiatives that promote positive mental health.</li> </ul>

<p><b>Eligibility Criteria Qualifications and / or experience</b> (continued)</p>	<p><b>Health</b> A candidate for and any person holding the office must be fully competent and capable of undertaking the duties attached to the office and be in a state of health such as would indicate a reasonable prospect of ability to render regular and efficient service.</p> <p><b>Character</b> Each candidate for and any person holding the office must be of good character</p> <p><b>Age</b> Age restrictions shall only apply to a candidate where he/she is not classified as a new entrant (within the meaning of the Public Service Superannuation Act, 2004). A candidate who is not classified as a new entrant must be under 65 years of age.</p>
<p><b>Skills, competencies and / or knowledge</b></p>	<p><b>Knowledge/aptitude:</b></p> <ul style="list-style-type: none"> <li>Demonstrate an understanding of recovery principles and a recovery-oriented ethos</li> <li>Demonstrate knowledge of Mental Health Services, Policy and planning processes</li> <li>Demonstrate high levels of analytical skills and rigour</li> <li>Demonstrate an ability to provide creative and innovative approaches to current Mental Health practices and an awareness of current best practices in other jurisdictions</li> <li>Demonstrate an ability to prepare and present reports</li> <li>Demonstrate a basic knowledge of and competence in use of Word, Excel and Email</li> <li>Demonstrate an ability to gather, assimilate, organise and communicate significant volumes of complex information in the context of decision making processes.</li> </ul> <p><b>Planning &amp; Organising:</b></p> <ul style="list-style-type: none"> <li>Demonstrate excellent organisational and time management skills to meet objectives within agreed timeframes and achieve quality results</li> <li>Demonstrate evidence of effective planning and organisational skills including an awareness of resource management and the importance of value for money</li> <li>Demonstrate the ability to improve efficiency within the working environment and the ability to evolve and adapt to a rapidly changing environment</li> </ul>

**Skills, competencies and / or knowledge (continued)**

- Demonstrate the ability to work to tight deadlines and operate effectively with multiple competing priorities
- A capacity to operate successfully in a challenging operational environment while adhering to quality standards.

**Leadership and Direction:**

- Demonstrate evidence of commitment to personal and career development, such as the DCU Leadership Programme
- Demonstrate knowledge of the bio-psycho-social model
- Display knowledge and experience of community development
- Demonstrate progressive, innovative and creative approaches in responding to challenges
- Demonstrate the capacity and personal resilience skills to operate effectively in a leadership role
- Demonstrate the ability to manage self in a busy work environment.

**Teamwork, working with and through others:**

- Excellent communication, interpersonal and networking skills including group facilitation and presentation skills
- An ability to support, develop and empower people in a challenging environment and within existing resources
- Team work skills, including the ability to work as part of a multidisciplinary team environment
- Leadership skills
- Lobbying and advocacy skills
- The capability to develop and sustain local feedback systems, mechanisms and structures
- The capacity for management responsibility and initiative as well as an ability to contribute to service development
- Motivation and an innovative approach to the job within a changing working environment, including responses to significant challenges in Service User, Family Member and Carer Engagement
- The ability to interact in a professional manner with other staff and all stakeholders
- The ability to be empathetic to others with different experiences and present the views of others fairly, accurately and objectively as required.

It is anticipated that the role may develop in time and this may involve managing people.

The above job description is not intended to be a comprehensive list of all duties involved and consequently,

**Skills, competencies and / or knowledge (continued)**  
**Other requirements specific to the post**  
**Competition Specific Selection Process**  
**Short listing / Interview**  
**Code of Practice**

the post holder may be required to perform other duties as appropriate to the post which may be assigned to him/her from time to time and to contribute to the development of the post while in office.

Access to transport as post will involve frequent travel.

Short listing may be carried out on the basis of information supplied in your application form. The criteria for short listing are based on the requirements of the post as outlined in the eligibility criteria and skills, competencies and/or knowledge section of this job specification. Therefore it is very important that you think about your experience in light of those requirements.

*Failure to include information regarding these requirements may result in you not being called forward to the next stage of the selection process.*

Those successful at the short listing stage of this process (where applied) will be called forward to interview.

The Health Service Executive will run this campaign in compliance with the Code of Practice prepared by the Commission for Public Service Appointments (CPSA). The Code of Practice sets out how the core principles of probity, merit, equity and fairness might be applied on a principle basis. The Codes also specifies the responsibilities placed on candidates, feedback facilities for candidates on matters relating to their application, when requested, and outlines procedures in relation to requests for a review of the recruitment and selection process, and review in relation to allegations of a breach of the Code of Practice. Additional information on the HSE's review process is available in the document posted with each vacancy entitled "Code Of Practice, Information For Candidates".

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## Appendix 7

### Reference Group Meetings

3 September 2014

1 October 2014

5 November 2014

3 December 2014

7 January 2015

4 February 2015

4 and 19 March 2015

14 and 15 April 2015

6 and 20 May 2015

3 and 16 June 2015

1 and 28 July 2015





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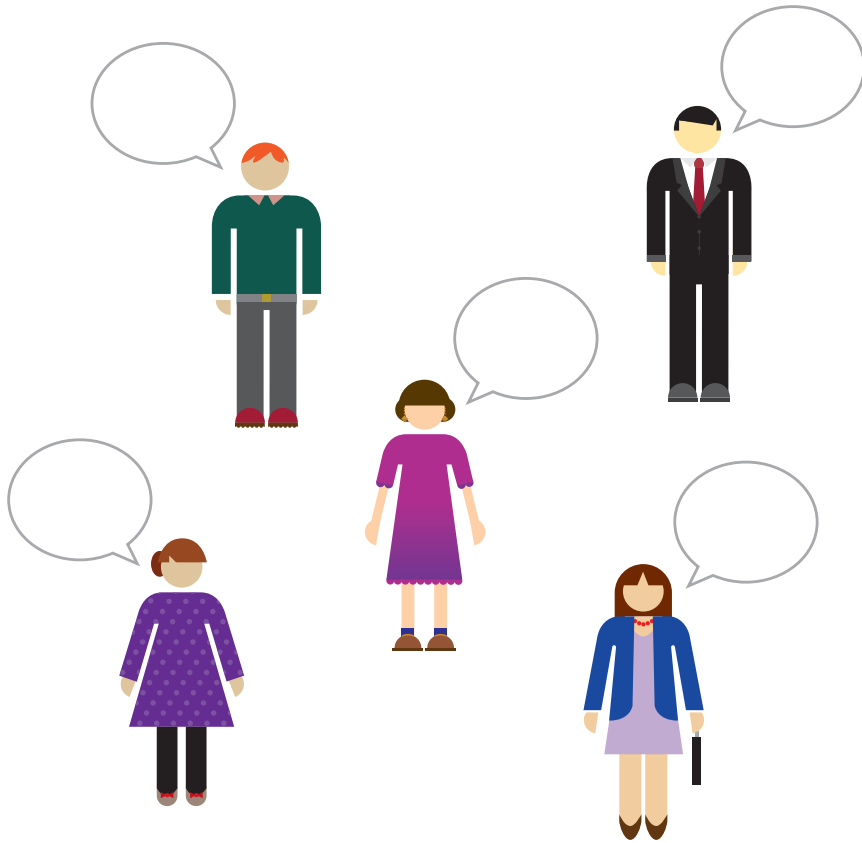
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