Going Beyond Harm

Event report from 31 August 2016
Introduction

Harm can come in many different forms, but an important – and often overlooked – form of avoidable harm is when carers’ views, knowledge and experience are not asked for or – worse – not listened to or accepted. The consequences of this for service users, staff and carers can be significant.

‘Going Beyond Harm’ was an event for carers of those who have been in contact with mental health services. The event included presentations, world café-style discussions and workshops. It was organised by Carers Trust Scotland and the Scottish Patient Safety Programme for Mental Health (SPSP-MH) and took place on Wednesday 31 August 2016 at the St Mungo Museum of Religious Life and Art in Glasgow.

Over the last four years, SPSP-MH has been working to improve and develop safety initiatives within hospital mental health services. The programme has succeeded in significantly reducing levels of harm across a number of areas, such as the safe use of medication, encouraging positive risk-taking among service users, improving staff interaction with service users and taking into account the views and concerns of service users. An area where the programme has sought guidance from Carers Trust Scotland has been around ensuring that the views of carers are represented and their concerns about their own safety and that of service users can be addressed as effectively as possible by mental health services.

Who was the event for?
The event was aimed at carers of people (adults, children or young people) with mental health problems who have, or may have, used mental health services, such as inpatient services or community mental health services. The event brought together carers and staff from mental health services throughout Scotland.

Aim
The aim of the event was to gather carers’ and staff views on how their involvement in services can help improve safety for service users, staff and carers within mental health services and, ultimately, share the learning with each other to support improvement and avoid harm.
Presentations
There were four presentations:

- Karen Martin (Carers Trust Scotland), setting the scene and introducing ‘The Triangle of Care’
- Johnathan MacLennan (Improvement Advisor, Scottish Patient Safety Programme for Mental Health), speaking about the programme to date and the importance of including service users and carers as partners in the programme
- Gráinne Smith, a carer who spoke of her own experiences that had encouraged her to become an author of advice books for carers, and
- Faye Mundell and Jacki Ishmael (NHS Dumfries and Galloway), on ‘The Triangle of Care in Practice – Experiences from NHS Dumfries & Galloway’.

World café conversations
A world café is a structured conversational process in which groups of people discuss topics at several different tables. A café ambience is created in order to facilitate conversation. There were four world café discussion topics and all participants attended each table in turn. Each discussion was limited to 15 minutes and the four topic areas covered are presented in Table 1.

<table>
<thead>
<tr>
<th>Table 1. Discussion topics</th>
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<td><strong>Medications</strong></td>
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| Discussion was focused on harm and medications and included:
  - concerns that carers, service users and staff have about medication
  - side-effects
  - administration of medication
  - collecting medication, e.g. hospital dispensary/community pharmacist/GP
  - dealing with compliance issues
  - depots. |
| **Admission and discharge**|
| Discussion was focused on harms arising from admission to and discharge from hospital:
  - admission procedures
  - involving carers in admission and discharge
  - consent to include carers (confidentiality)
  - information
  - stress or distress during admission and discharge. |
| **Moving between services** |
| Discussion was focused on transitions such as from the ward to pass, from intensive psychiatric care to an open ward, from hospital to community or from adult to child and adolescent wards and the possible harms that may occur, such as:
  - communication and information for service users |
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<tr>
<th>Involving carers</th>
<th>Discussion was focused on how carers are involved in the care:</th>
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<tr>
<td></td>
<td>• Do they feel listened to?</td>
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<td></td>
<td>• Do they feel informed?</td>
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<td></td>
<td>• Do they get involved in care (e.g. invited to meetings)?</td>
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<td></td>
<td>• Confidentiality and consent</td>
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<td>• Experience of visiting an inpatient.</td>
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There were eight table groups and participants stayed with their group for the duration of the world café whilst moving around the specific topics.

Each table had two facilitators and participants included carers, service users and staff from various mental health services across Scotland. Notes from the discussions were recorded on paper ‘tablecloths’ and the results of the discussions were transcribed for analysis.
Workshops
Following the world café conversations, a workshop was held to allow participants to further explore the concepts that had arisen from the session. Participants remained in the same groups for the workshop and Post-it notes and flipchart paper was used to record discussions. Each of the four discussion topics from the world café sessions was discussed in turn.

Analysis and results
All written records from the event were imported into NVivo®, a qualitative analysis software tool. Word frequency analysis queries were run and word clouds were created. A simple thematic analysis was conducted for each themed discussion.

Discussion area 1: Admission and Discharge
Listen, communicate, inform and support carers during admission and discharge
Participants highlighted the challenges of accessing inpatient services owing to bed shortages, suggesting that admission should be based not on the availability of beds but on clinical need. For example, one carer said he struggled to access sufficient crisis-level services for his son and was unable to do so until his son took an overdose and was referred from Child and Adolescent Mental Health Services (CAMHS) to an inpatient unit.

Carers indicated that admission can be a challenging time for them and a stigmatising experience for service users; they did not feel supported to cope with the stress of leaving the person for whom they are caring in an inpatient unit.

There were more concerns about discharges than admissions. Failing to communicate and involve carers with discharge planning was a key concern. Carers indicated that they could provide insight into whether or not a service user was ready for discharge, as well as supporting staff and the service user with discharge and future crisis planning.

World cafés – What is harm?
Related to a lack of involvement in care planning, carers reported the issue of feeling unsupported to cope when the person for whom they are caring is discharged and they had to take over their care, sometimes with limited notice. Engagement with carers during discharge planning was described by some as ‘token’ and inconsistent, more of an ‘afterthought’ than genuine engagement. Failure to involve carers in discharge decisions and planning was seen by some as a lack of ‘respect’ for their knowledge and their crucial support role with the service user.
Inadequate communication between carers and staff was highlighted as a challenge during discharge planning. Failures in communication between different services, such as inpatient services and community-based teams, was also highlighted. One example given was families not being made aware that the person they care for had been discharged. Carers suggested that failure to listen to them was a safety risk, as they hold important information on medication and the service user’s state of mind, which could be used for risk assessment during admission and discharge. Variation in standards of care at admission and discharge was raised. ‘Luck’ was considered a factor in this due to large variations in practice amongst staff members.

Confidentiality

Issues of confidentiality were discussed in relation to challenges in communication between carers and staff. One carer raised the issue of not feeling informed about his son’s medications and state of mental health at discharge due to staff concerns about confidentiality. The discussions raised the idea that confidentiality and data protection can be used as an ‘excuse’ to not inform or involve carers in decision-making about admission and discharges.

Communication – feeling listened to and informed

Discussions highlighted the importance of carers feeling ‘listened to and respected’, not just ‘being mined’ for information about the person they care for and then left unsupported. Feeling listened to and supported meant an opportunity to ‘tell your story’ and ‘voice concerns’, as well as to share and seek information about the service user. Carers suggested that when they are listened to by services they can help prevent admissions by alerting services about a crisis and possibly avoiding an admission.

When carers are given sufficient information and support during admission and discharge it helps them to feel hopeful after discharge and enables them to resume caring for the service user. Failure to provide sufficient information was considered a risk to safety and a potential harm to the service user and their carer.

Alternatives to admission

The groups suggested that admission should be the last resort and all alternatives should be considered beforehand. Crisis teams were the main alternative discussed, and the lack of investment in these services was raised. Other services that could prevent admission suggested by participants included support in the home, day services and supported activities for service users. People suggested that social issues may often be the trigger for a crisis and admission; they suggested alternatives are required or carers are left to deal with service users’ distress and problems.
In the workshops the groups were asked to consider what ‘good’ and ‘improved’ looked like. In many cases these were described as already happening but only in ‘pockets’ and ‘not every time or all the time’. The following points are some of the suggestions for improvement:

- Named contacts to talk to about concerns during admission and after discharge.
- Share information about how services work at admission and discharge with carers, e.g. leaflets about admission and discharge letters.
- Involve carers in discharge and crisis planning.
- Involve carers in the admission process and explain procedures for medication, role of staff, etc.
- Details of support services for carers to be shared at admission and discharge.
- Offer education and training for carers about discharge and care planning.
- Use advance statements while the service user is well, to give permission for the future involvement of carers.
- Staff should be encouraged to contact and talk to carers when they need information.
- Transition workers can support service users and carers after discharge.
Discussion area 2: Medications

Involving and informing carers

The groups raised the lack of information and education provided for carers about psychiatric medications and their active effects and side-effects. Participants wanted information on why a medication had been prescribed and how it is supposed to work. Carers indicated they did not feel that healthcare professionals communicated with them enough about medication. They indicated that it would be more helpful to actively involve carers in medication reviews, so that they are more aware of the decision-making process and any issues around the use of medication. There is a ‘need for more dialogue and working together between people and carers’ to avoid harm that results from a failure to understand the potential benefits and harms of medications. Although a lack of information was mentioned frequently, some carers emphasised their expertise about medication, which they felt was not acknowledged.
Compliance, choice and service users’ relationship with carers

Service users suggested that carers can be led to believe that medication is the only solution for people with mental health problems. The lack of information and education for carers about side-effects, including the possible long-term detrimental physical effects of medication, makes it difficult for them to understand why service users might not comply with medication. They may be faced with the decision of whether to inform professionals that the service user has stopped taking their medication. Carers may take on a role in encouraging compliance with medication regimes, which can have a detrimental impact on their relationship with the service user and lead to conflict.

‘I don’t phone up to ask “how are you?” I phone up and ask if they’ve taken their medication’

It is also a considerable burden on carers, who feel they have to ensure that the person for whom they care takes their medication and can be placed in the position of arguing, in a formal medical setting, that the service user should be given medication against their will.

Service users emphasised choice and wanted more information for carers and themselves about alternatives to medication, such as psychological therapies. They also wanted their right to make choices about medications, including reducing or stopping medication to be acknowledged and supported by carers and professionals, rather than being a ‘power struggle’. Service users described ‘struggling to communicate’ with others about the impact
of medication on their physical health because of side-effects. Further discussion suggested that some people do not feel that the physical impact of side-effects are acknowledged and ‘over-medication’ and its impact on health and life expectancy is also not acknowledged.

Carers and service users also raised the difficulties of managing contradictory guidance and advice about medication from professionals. The main conflict raised was between general practitioners (GPs) and psychiatrists, with examples of GPs ‘over-ruling’ psychiatrists’ prescriptions, leaving people confused and worried.

**Side-effects and physical well-being**

Concerns about side-effects and medications’ physical impact on service users’ long-term health was a focus of discussion. Concerns raised included:

- Failure to monitor and record side-effects and helping people to manage them
- Failure to acknowledge how harmful side-effects can be for short- and long-term health
- Lack of education and information about side-effects
- Polypharmacy (prescribing of multiple medications) issues and its impact on health
- Stigma resulting from physical side-effects

**Discussion area 3: Moving between services – transitions**

**Access to services**

Discussions highlighted the difficulty in accessing services before issues of moving between services even arise. Harm can arise from desperation as people struggle to access care and ‘get into the system’. One example given was carers resorting to calling the police in an effort to gain access to services for the person they care for, which can lead to the person getting a criminal record. When services require referral from a GP it can be very frustrating for carers, who struggle to get the unwell person they care for to attend the GP practice; it was suggested that carers should be able to refer directly to more services.

**CAMHS to adult services**

The transition from CAMHS to adult services was considered a major one because the services have ‘different values’ and cultures. Participants suggested that this transition is made more difficult because of communication failures between CAMHS and adult services and a failure to communicate with service users and carers about the differences. Another difficulty highlighted was the gap in service provision for young adults in the 16-25 years age range.
**Adult to older adult services**

Groups indicated that people can feel they are moved to older adults services ‘against their will’ when they become 65 years old, which was considered too young to be moved to older adult services. One participant suggested that some people tend to be ‘forgotten’ by mental health services once they reach this age.

**Lack of information during a move between services**

The major concern raised about people’s experiences of transition between services was a lack of communication and information about what would change. This included information on referral, waiting times to first being seen, what the new service would be able to provide and what would no longer be provided. An example of this was access to family therapy.

This lack of information was considered problematic because the level of input from professionals can deteriorate rapidly following a transfer, such as from an inpatient unit to community services. The discussions also suggested that there are challenges with services and professionals communicating with each other, for example between community psychiatric nurses (CPNs) and inpatient services.
Communicating with carers during transitions between services

As previously mentioned, carers do not feel adequately involved in either discharge from and admission to services or the process of moving between services.

Confidentiality was raised as a barrier to the involvement of carers in transitions. Participants suggested both that staff were afraid of breaking confidentiality and they may sometimes ‘hide behind’ confidentiality to prevent the involvement of carers. Discussion suggested that people require training and advice on what can and cannot be shared with carers and how to request permission from service users to share information.

Groups suggested that this lack of communication with carers can lead to missed opportunities, which could prevent admissions, relapses and even delays in recovery.

Carers’ suggestions for improvement

From the group discussions, two key areas for improvement were highlighted:
• Education for staff on information for carers and issues of confidentiality and consent to share information during admission and discharge
• Carers should be involved in an initial handover meeting when accessing a new service.

Discussion area 4: Involving carers

Value, validate and recognise the role of carers
Carers may be left feeling excluded and ‘ignored’ and ‘angry’, particularly if they feel their views and caring role are not respected. The discussions suggested that carers can feel ignored and excluded by professionals and services. They suggested that services tend to ‘ask the carers last, if at all’, which can lead to frustration and a lack of trust or faith in professionals and services. Carers were also concerned that the failure to involve and communicate with them about the well-being, mental state and care of the person they care for has the potential to lead to harms for the service user.

If professionals worked in partnership with carers then crises could be avoided and recovery promoted through the sharing of information and joint planning to support the service user. Some carers indicated that in order to be involved in the care of their relative they must be highly persistent in requesting input from staff and providing information or they would be excluded.

‘From the start of my son being in hospital, we have asked to be involved – sometimes
Some carers indicated that they did not feel understood or respected when communicating with some professionals, which can be interpreted as a lack of compassion and empathy with the carer’s situation. They suggested that communication could be improved by using some basic marks of respect and compassion, such as asking ‘how are you?’ or introducing themselves when first meeting and attempting to see things from the carer’s perspective.

Confidentiality

The discussions highlighted the challenge posed to carers and staff in how to approach issues of service users’ rights to confidentiality. Some carers suggested that confidentiality is used by staff as an excuse to actively exclude the carer from the service user’s care in a way that would not be acceptable in a physical health setting:

‘If it was oncology would they say “we’ll give your child chemotherapy but won’t discuss it with you”?’

A number of discussions centred on carers’ rights are not being given adequate weight in the debate about confidentiality, and the failure to share information makes it very challenging to care for someone. Participants suggested that professionals could benefit from training and guidance to know how to manage confidentiality in a way that allows the sharing of key pieces of information.
Carers also suggested that their confidentiality is not always given the same value as service users. Some carers said information that they had shared about the person they care for (in confidence) has then been shared with the service user and that this can be damaging to the relationship.

Support for carers
Carers made it clear that their caring role can be very stressful and demanding. Examples of additional stressful aspects of caring included leaving the person they care for in a locked psychiatric unit or witnessing the restraint or ‘sectioning’ of them. Having to talk at large multidisciplinary meetings and sometimes having to disagree with the position of the multidisciplinary team can be intimidating and may be damaging to relationships. Some carers mentioned feeling ‘blamed’ for the problems of the service user and would appreciate the offer of support and compassion from professionals to help them to deal with the stress, anxiety and guilt they may experience.

Carers’ suggestions for improvement
Potential suggestions for areas of improvement from discussions on the day included:

- Develop governance/pathways for involving carers and training for professionals around information sharing/confidentiality and communication with carers
- Make available support and psychological therapy for carers, e.g. behavioural family therapy
- Share information with carers about available support and how services work
- Have a carer representative (professional or member of the public) at professional meetings
How do we sustain ‘Going Beyond Harm’ conversations into the next year?

During the day, there was a clear message that this must be the start of an ongoing programme of improvements and the start of the conversation. Based on this, the following have been agreed:

- A commitment from SPSP-MH and Carers Trust Scotland to deliver four more regional events in Oban, Perth, Aberdeen and Dingwall, with plans to hold similar events in the south of Scotland.
- The teams will generate and share information and carer experiences based on these events, with the running themes identified in this report.
- The team will share this report with colleagues at Scottish Government and Health and Social Care Partnerships.
- The team will continue conversations to establish what a measure of success looks like: share what is good practice and how carers, service users and services will notice improvement.

World cafés – What is Harm?

Both SPSP-MH and Carers Trust Scotland would like to thank all those who attended on the day for giving their time and sharing their experiences and for the generous and open manner in which this occurred.
Appendix 1. Going Beyond Harm Attendee Breakdown

Not including the organisers, 60 delegates attended the event and 40 completed evaluation forms were received.

Table 1 Attendee breakdown:

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<tr>
<th>Organisation</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Carer Organisations</td>
<td>28%</td>
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<tr>
<td>Carers</td>
<td>39%</td>
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<tr>
<td>NHS</td>
<td>18%</td>
</tr>
<tr>
<td>Other</td>
<td>12%</td>
</tr>
<tr>
<td>No response</td>
<td>3%</td>
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Appendix 2. Going Beyond Harm Evaluation Responses

What would you like to see as a result of this event?

‘Early roll-out of Triangle of Care on a mandatory basis throughout mental health care in NHS Scotland as a means of having better carer input into care.’

‘Implementation of Triangle of Care across mental health and shouldn’t that be a component of all care? Developing and sharing good practice.’

‘Triangle of Care being implemented across health boards in Scotland.’

‘Sharing of experiences and development of carer engagement good practice and the direct improvement this can have on patient care.’

‘Better communication between services and carers.’

‘Improve services and practices around care for service users and carers.’

‘Involvement and communication across the Board to work in partnership.’

‘More involvement with carers at the beginning of the journey.’

‘Scottish Government should recognise that caring for mental health is unique and needs specialist services to include and involve carers.’

‘Awareness of carer across all services.’

‘Spread the word about the value and savings carers provide (monetary, preventing further deterioration etc).’

‘The good work that is ongoing across the country needs to be shared.’

‘Greater understanding of a carers importance, and benefit of carers comments.’
Reasons why a tool such as the Triangle of Care should be standard practice in mental health services?

‘It is the basic 'caring side' that is needed.’

‘Absolutely. The tool covers all the areas that we keep missing.’

‘It makes sense! Can influence culture change.’

‘It signposts services and offers a framework to begin to make change.’

‘Improving our engagement with carers and working in partnership increases safety and reduces harm. I have the experience firsthand to provide evidence that this is the case.’

‘Involvement from carers is essential to provide person centred care. Needs to be in Older Peoples Services!’

‘Feel that when you need help there is something in place to get help.’

‘I think the Triangle of Care would improve services for users and their carers hugely.’

‘Continuity of care across the service and councils.’

‘Carers should have support and information right from start of their caring role. Carer Aware Training for all staff and they should be monitored to make sure that it is happening.’

‘Care for carers is inadequate. The Triangle of Care can sort this!’

‘Please involve carers routinely at all steps. It is better for everyone.’

‘They have implemented the T.O.C.. Significantly improving carer engagement leading to increased safety and decreased risk to patients. Improving patient centred care.’
Was there anything from the event you would like to take forward, either within your carer service, your service user forum or service?

‘All of it - the groups gave me lots of information which as a professional I will remember and hope it will influence my practice.’

‘Sharing of experiences is very informative.’

‘Feedback, ideas and experiences shared at event. How this can improve carer engagement with health care services.’

‘Triangle of Care resources.’

‘Carers and services feedback and examples of good practice to improve carer engagement and improve safety, reduce harm.’

‘Discuss practical ways to involve carers within Homeless Occupational Therapy Service where I work.’

‘Will feedback triangle of Care to our Head of Services...’
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