

1 **Involving carers in risk assessment: a study of a structured dialogue between mental**
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4 **health nurses and carers**

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9
10 **Abstract**

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13 Background: Involving carers is a key priority in mental health services. Carers report the
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15 sharing of service users safety information by mental health nurses is problematic and seldom
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17 takes place.
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21 Aims: To investigate the impact of an intervention on consensus between nurses and carers
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23 on perceptions of risk.
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26 Methods: Carer-nurse risk consensus scores were measured pre- and post- introduction of a
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28 structured dialogue (paired t-test/ANOVA). Carer experience with involvement was surveyed
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30 pre-test ($n=60$) and compared with the post- test intervention group ($n=32$) (chi-square tests
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32 of linear-by-linear association).
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37 Results: Consensus and perceptions regarding type and severity of risk did not change
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39 significantly for carers or nurses after engaging in a structured dialogue. Statistically
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41 significant differences were found with carers' reporting higher levels of satisfaction with
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43 services in 4 out of 6 areas surveyed.
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47 Conclusions: Findings provide support for increasing carer contribution to discussions
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49 regarding risk. Further work to embed carer involvement in clinical practice is warranted.
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Introduction

A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without support (Carers UK, 2017). Carers have a crucial role to play in the delivery of high quality mental health services (Happell et al., 2016). Best practice should see a collaborative approach to care between professionals, service users and carers (Worthington et al., 2013). Involving carers is a key part of international policy and guidance (Australian Government, 2010; US Substance Abuse and MH Services Administration, 2009; UK Department of Health [DOH], 2010, 2014). Estimates suggest the 1.5 million carers of people with mental health issues in the **United Kingdom** contribute in excess of £26 billion to the UK economy (Carers UK, 2017).

Caring for a person with mental health difficulties can have considerable effect on the wellbeing, mental or physical health of carers (Carers UK, 2017). However, involving carers may increase their satisfaction with services, reduce stress and burden, plus provide them with a sense of empowerment (Campbell, 2004). Despite literature advocating carers could and should contribute to care, current levels of family and carer involvement remain tokenistic (Gee et al., 2016), variable, inadequate and aspirational (Stanbridge et al., 2009). Carers should be involved in the assessment and management of risk and service user safety (Clancy et al., 2014; National Patient Safety Agency, 2009; DOH, 2014). Yet serious incident investigations and media reports all too often highlight anger and recrimination from families or carers of mental health service users towards services for failing to listen to their concerns. By ignoring carer views or failing to inform them of significant events, their ability to provide support effectively post discharge compromises both their safety and that of the service user they support (Gray et al., 2008). Equally the involvement of service users in

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3 discussions regarding care and service user safety is not consistently undertaken within
4
5 mental health care settings (Simpson et al., 2016).
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9 When dialogue does take place between professionals and carers, it can be difficult as
10
11 professionals' perception of what constitutes risk (Farrelly et al., 2012), how they prioritise
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13 risk (Ryan, 2002) and even the language they choose (Clancy et al., 2014) does not
14
15 consistently reflect that used by carers. Whilst a number of different healthcare professionals
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17 may be involved in assessing risk and service user safety, in acute settings this dialogue is
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19 often the responsibility of nurses. Carers complain nurses use technical, patronising or
20
21 disempowering language (Chatzidamianos et al., 2015). Capacity for meaningful discussion
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23 is therefore limited leaving families and carers unable to communicate vital information
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25 which could provide a more comprehensive representation of the service users' illness.
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27 Coffey et al. (2017) reported nurses are sometimes reluctant to discuss risk with carers for
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29 fear of facing disagreement or causing upset, whereas Crombie et al. (2007) argued the main
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31 barrier to communication and carer involvement is conflict between service users' right to
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33 privacy and confidentiality against carers' need for information. Such dilemmas see nurses as
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35 well as other health care professionals unclear about what can and cannot be shared and use
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37 this as a way to avoid engaging with carers (Gray et al., 2008).
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45 There remains a gap between the rhetoric in policy, legislation and implementation of carer
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47 strategies (James, 2016). Policy and best practice states carer knowledge of service users
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49 should be used to build comprehensive and accurate pictures to inform assessment and
50
51 support clinical management planning (Gray et al., 2008). However current levels of
52
53 involvement offer limited opportunities for both service users and carers to manage safety
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55 (Coffey et al., 2017), and carer involvement continues to be poorly implemented and defined
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57 (Cree et al., 2015). Coffey et al. (2017) reported service users and carers were often unaware
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3 risk assessments had taken place or what they contained suggesting guidance surrounding the
4 listening, obtaining and sharing of information has yet to be embedded into practice. In
5
6 addition, the quality of risk assessments vary in depth and detail (Gilbert et al., 2011), are
7
8 incomplete or even misunderstood (Cree et al., 2015).
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13 It remains unclear what joint risk assessing interventions would look like and how these
14 would be delivered in practice (Worthington et al., 2013). How this gap might be effectively
15 tackled is unclear as currently those responsible for assessing risk in acute settings such as
16 nurses, lack the skills, training and confidence necessary to work with carers effectively
17 (Stanbridge et al., 2013). This paper describes an intervention undertaken to promote a
18 structured dialogue between nurses and carers regarding concerns about service user safety
19 and risk. The aim of the study was to investigate the impact of increasing the involvement of,
20 and level of contribution that carers make to risk assessments. Specifically;
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33 (1) What impact does involving carers in risk assessment have on the consensus between
34 carers and nurses about the areas and levels of risk a service user presents with? and
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38 (2) What impact does involving carers in risk assessment have on their levels of satisfaction
39 around their involvement with risk assessment and services?
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44 **Design**

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47 The study had a pragmatic non-randomised design and used two separate groups of carers. It
48 was not practicable to randomise carers as once intervention training had been delivered to
49 nursing staff, practice may have changed.
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54 **Methods**

55 *Setting and Sample*

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3 The host organisation was a healthcare provider in the north of England delivering mental
4 health services to a mixed urban and rural population across a number of inpatient units for
5 service users aged between 18 and 65 years old. Units were located upon separate
6 geographical sites but all subject to the same policy and procedural guidance.
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13 Carers were all supporters of adults with a range of psychiatric disorders. Group A consisted
14 of 60 carers of service users admitted to one of the units between November 2014 and April
15 2015. Group B consisted of 36 carers of service users admitted between June 2015 and April
16 2016. As per standard practice, at the point of admission, the care team established whether a
17 service user had a family member, friend or carer involved in their care. Only carers of
18 service users who had signed a 'Permission to Share Information' form (a standard document
19 used within the service and filed within their clinical records) were invited to participate in
20 the study. Age parameters were not set for carer participants as demographic details are not
21 collected by the service.
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34 35 ***Data Collection***

36 37 38 *Carer Experience Data Capture Survey*

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41 As no validated questionnaire to measure carer satisfaction with involvement in risk
42 discussions was identified, the Carer Experience Data Capture Survey was developed by the
43 research team and approved as appropriate by independent carers not connected to the study.
44 This was not however subject to testing for reliability and validity. The six-question survey
45 asked carers to rate satisfaction with their level of involvement in discussions about risk and
46 overall satisfaction with the service using a 5-item Likert rating scale with the options: "A
47 lot", "Quite a bit", "Moderately", "A little", "Not at all" (see Table 2).
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59 *Group A*

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3 Group A carers only completed the Carer Experience Data Capture Survey. Eligible carers
4 were identified from clinical notes by the research team and posted a letter between seven
5 and ten days post admission giving details of the survey. They were contacted two to three
6 weeks later and invited to complete the survey over the telephone. Data provided a baseline
7 for carer satisfaction regarding the experience of supporting a service user admitted to the
8 local service.
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10 11 12 13 14 15 16 17 18 *Group B*

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21 Data collection from the intervention Group B commenced in June 2015. The intervention
22 required a member of nursing staff to engage the carer(s) in a structured dialogue focussed
23 upon their concerns about the risk and safety of the service user they supported. Recruitment
24 was undertaken by nursing staff as they assessed capacity of service users and had carer
25 contact. All carers eligible had the chance to participate. Service users were approached and
26 consented for permission to approach carers. Carers were then provided with an information
27 sheet to explain the purpose of the study and invited to participate in the structured dialogue.
28 Group B carers completed the intervention at a time convenient for them and with a nurse on
29 the ward where the service user they supported was receiving care. Two to three weeks later
30 they were contact by telephone by a member of the research team and invited to complete the
31 Carer Experience Data Capture Survey.
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47 *The structured dialogue intervention*

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50 The intervention consisted of a face to face structured dialogue based upon the GRIST
51 (Galatean Risk and Safety Tool) (www.galassify.org/grist) web-based decision support
52 system collecting contextual and historical data, in addition to the immediate risk history and
53 current behaviour. GRIST was developed in the UK and combined both clinical and actuarial
54 approaches to risk assessment. It contained six areas of risk: suicide, self-harm, harm to
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3 others/damage to property, self-neglect, risk to dependents and vulnerability. Although it has
4 not been subject to independent evaluation, GRIST was one of three multiple risk tools
5 recommended in Best Practice in Managing Risk (DOH, 2007). Furthermore, the authors
6 claim it demonstrated outcome validity ([www.egrist.org/sites/egrist.org/files/grist-](http://www.egrist.org/sites/egrist.org/files/grist-summary_0.pdf)
7 [summary_0.pdf](http://www.egrist.org/sites/egrist.org/files/grist-summary_0.pdf)). GRIST was chosen as this was the risk assessment tool that clinicians were
8 required to use in the host organisation. Practice as usual was for GRIST to be completed for
9 each service user by a nurse on referral to the service. This should have been updated to
10 reflect significant events or new information. Professionals completing GRIST rated each
11 area of risk using a numerical scale (0-10) for each concern. For the purposes of this research,
12 the numerical scale (0-10) on the GRIST was replaced with an 11 point visual scale ranging
13 from green through orange and red. Green represented no risk (0), orange a mid-point
14 (around 5 or 6), and red extreme risk (10). Carer advisors to the project suggested a visual
15 scale would be more acceptable and easier for carers to use during the structured dialogue
16 between nurse and carer and approved its inclusion for use.

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Nurses involved had all received risk assessment and GRIST completion training as part of
their clinical role independently of this study. Family and carer engagement training was not
provided by the researchers although was on offer to nurses via their organisation. In
preparation for conducting the intervention, in May and June 2015, 41 nursing staff from the
participating units attended a one hour training session delivered by two members of the
research team experienced in delivering clinical practice based training. Training focused on
guiding staff through the completion of the key worker / carer interview recording sheet.
Detailed instructions for completion of this recording sheet were provided in the form a script
to guide the discussion between nurse and carer to promote consistency. A member of the
research team assessed each nurses understanding of the intervention and ability to follow the
script using role play at the end of the training session. The ability of the nurses to engage

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3 with carers was subject to their 'practice as usual'. As standard practice nurses within the
4 service were expected to identify, liaise with and signpost carers for further support. All
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8 nurses trained were deemed competent to deliver the structured dialogue. A member of the
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The nurse instigated the intervention following the format shown on the key worker / carer
interview recording sheet. This started with a general question 'What three things keep you
awake at night' and then proceeded with a discussion focussing upon each of the six areas of
risk. The GRIST risk rating undertaken by the nurse on admission was used as the pre-
discussion nursing score and provided a starting point for each discussion. For each area of
risk the nurse would share the pre- discussion nursing score and ask the carer to indicate and
record on the visual scale the pre- discussion carer score. A dialogue would then take place.
The carer was then asked to indicate their post- discussion score. Changes to the nurses'
perception of the risk posed by the service user as a consequence of the discussion with the
carer were recorded as per standard practice when new information was received. Three days
after the intervention, the service users' GRIST was accessed by the research team and used
as the post- discussion nurse score to assess if the nurse had updated the risk assessment held
by the service.

Outcome Measures

The primary outcome measure was the carer and nurse pre- and post- discussion scores
recorded on the interview recording sheet (for Group B only), relating to their perceptions of
risk across the six areas of the GRIST.

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3 The secondary outcome measure was carer experience data collected from both Group A and
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5 Group B carers two to three weeks post admission or participation in the intervention.
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9 *Statistical method*

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12 For the purposes of analysis the visual scores were converted back to their numeric
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14 equivalent. An effect size of 0.4 was anticipated for the change in mean totals for the primary
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16 outcome measure (GRIST Consensus Scores) after discussion and a before-after correlation
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18 of 0.5 was anticipated. A paired sample t-test of the before and after means of the primary
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20 outcome measure required 52 participants to achieve 80% power using a 5% significance
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22 level for testing (G Power, Version 3.1.9.2).
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27 The absolute value of the difference between carer and nurses total GRIST pre- discussion
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29 scores was calculated to give the pre- discussion discrepancy score. This calculation was
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31 repeated on the total GRIST post- discussion scores to give the post- discussion discrepancy
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33 score. Differences between the two discrepancy scores (pre- score minus the post- score)
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35 were then calculated and significance was tested using a paired t-test. The changes were
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37 analysed by one-way ANOVA to test for any differences between the four locations (clinical
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39 units) in the host organisation used for the study. Bootstrapped p-values and confidence
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41 intervals were used as a precaution in case of violation of the standard assumptions for the
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43 paired t-test and one-way ANOVA.
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48 Carer satisfaction responses for each of the six questions asked were summarised
49
50 descriptively with the figures reflecting the percentage and number of carers giving a positive
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52 response. Differences in satisfaction between the intervention (Group B) and the comparator
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54 group of carers (Group A) were tested using chi-squared tests of linear-by-linear association.
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Results

Clinical pressures and the withdrawal of the GRIST as the preferred risk assessment tool of use within the host organisation impacted upon recruitment so only 36 Group B carers participated in an intervention rather than the required 52. In addition, missing data on some components of the GRIST for either the carer or the nurse pre- or post- discussion resulted in 32 sets of carer-nurse pairs being available on which to calculate GRIST discrepancy scores (see Table 1).

Table 1 Paired t-tests for GRIST Carer-Staff Consensus Scores

GRIST component	Mean Change in Discrepancy Score	Standards Error of Mean Change	95% Confidence Interval for Mean Change	t	p-value
Suicide	.156	.404	(-.625,1.03)	.386	.674
Self-harm	.781	.470	(-.094,1.75)	1.66	.105
Harm to others or damage to property	.188	.427	(-.656,1.03)	.439	.679
Self-neglect	.469	.435	(-.374,1.31)	1.08	.308
Risk to Dependents	.281	.346	(-.375,.969)	.814	.459
Vulnerability of Service User	.594	.386	(-.156,1.34)	1.54	.152

n=32 for all GRIST components; positive mean change for a component indicates that carer and staff converged in assessment following the intervention. Bootstrapped p-values and 95% CIs based on 1000 bootstrapped samples are presented.

The mean pre- discussion discrepancy score was 10.7 (SD=9.81). Whilst the mean post-discussion discrepancy score was 9.56 (SD=7.69). Convergence between carer and nurse perceptions **of risk** would be indicated by positive changes to discrepancy scores. The mean

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3 change in discrepancy score was 1.16 (SD=1.29) which was not statistically significant
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5 (t=0.891, df=31, p=0.391, 95% CI (-1.19, 3.88), effect size= 0.158). It had been anticipated
6
7 that there would be convergence between carers and nurses in their perceptions of risk
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9 following their discussions however the results did not support this assumption as carer-nurse
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11 consensus regarding overall risk did not change substantially. No significant differences
12
13 between the four individual inpatient units were found from the one-way ANOVA
14
15 (F(3,28)=1.00, p=0.407), although it should be noted that three of the four units contributed
16
17 very few carer-nurse pairs due to staff turnover and resourcing issues. Mean changes for each
18
19 of the six specific risk areas of the GRIST in carer-nurse discrepancies were in a direction
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21 consistent with increased convergence but again were not statistically significant. The effect
22
23 sizes for convergence in GRIST scores between carers and nurses undertaking the
24
25 intervention pre- and post- discussion were not significant in any of the risk areas measured.
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27 Although risk related to self-harm showed greatest movement in terms of consensus, with
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29 p=0.105.
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36 Within-person changes in the GRIST component ratings pre- and post- intervention were also
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38 examined for carer and nursing groups. Most people, both carers and nurses, did not change
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40 their ratings pre- to post- intervention for any of the areas of risk. However there was a lack
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42 of post- intervention nurse scores, with only 25% of risk assessments being updated within 72
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44 hours of the dialogue.
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48 Carer experience data (see Table 2) showed generally, a greater percentage of carers who
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50 participated in the intervention reported higher levels of satisfaction-as opposed to Group A
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52 carers who had received service as usual. Group B carers demonstrated higher levels of
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54 satisfaction across all six questions, four of these areas being statistically significant. Overall
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56 satisfaction with the admission was higher, going from 41.6% to 88.2%. Plus a total of 85.3%
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of carers in Group B were satisfied that they had been given opportunity to discuss their concerns, 26.9% higher to the score recorded for Group A. Q4 and Q5 related to carer satisfaction that nursing staff focussed upon the right area of risk and understood the severity of the carers' concerns. Carer satisfaction that nurses acknowledged the severity of the risk was rated at 85% for carers in Group B, more than twice that of Group A. Higher levels of carer satisfaction regarding nursing teams sharing information and carers feeling involved in the decision making process was insignificant, with more than 20% of carers not responding positively.

Table 2 – Carer Experience Data Capture Survey Results

Question	Group B Percentage Satisfied (Number/Number Responding)	Group A Percentage Satisfied (Number/Number Responding)	Chi-square test value for linear by linear association (df=1 in all cases)	p-value
Q1. Did you get the opportunity to say what you were worried about?	85.3% (29/34)	58.4% (35/60)	15.8	<0.001
Q2. Did the care team share what they were worried about?	78.8% (26/33)	62.7% (37/59)	1.65	0.202
Q3. How involved did you feel in the decisions made about risk?	78.8% (26/33)	72.9% (43/59)	0.104	0.764
Q4. How satisfied were you that they focussed on the right area of risk?	85.2% (29/34)	53.7% (29/54)	14.2	<0.001
Q5. How satisfied were	84.8% (28/33)	40.0% (20/50)	20.8	<0.001

you that the care team understood the severity of the risk?				
Q6. Overall how satisfied were you with the service?	88.2% (30/34)	46.6% (27/58)	26.3	<0.001

Likert scale responses for each question were labelled “A lot”, “Quite a bit”, “Moderately”, “A little”, “Not at all”. Percentages reported above are the percentages of respondents who gave one of the first three responses.

Discussion

This study demonstrated that carers who took part in the structured dialogue were more satisfied overall with their experience of supporting a service user through an inpatient admission than those in the comparator group. In addition, carers given the opportunity to discuss risk expressed higher levels of satisfaction at being able to voice their concerns in terms of both the area and severity of risk. This supports evidence suggesting carers place great importance in regards to being heard (Worthington et al., 2013) and being given the opportunity to contribute to care (Cree et al., 2015). Furthermore, as with carers who were involved with care planning and supporting a service user (Simpson et al., 2016), carers in this study were not convinced they were equal partners and did not feel any more significantly involved in decisions. It is difficult to say with any certainty if individual carer dissatisfaction was due to criticisms around the level or quality of contact, or feelings that nursing staff misunderstood or did not take into account what they said.

The provision of a structured dialogue did not provide overall statistically significant difference in changes to perceptions of risk for either carers or nurses across a range of areas of risk. In fact neither group substantially altered their ratings across any of the risk domains. Therefore despite delivery of an intervention that aimed to increase discussion and sharing of

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3 views on risk, neither group changed their perceptions as a consequence of this discussion.
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5 Within person changes were also minimal. These findings may suggest that nurses either did
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7 not gain new information, did not listen to carers or failed to update risk assessments,
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9 however this is conjecture as further follow up with staff was not conducted. The lack of
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11 updating or change to post- discussion nurse scores does mirror findings by Gilbert et al.
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13 (2011) who found mental health inpatient nurses unexpectedly record a low number of risk
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15 assessment reviews.
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21 As found by Littlechild and Hawley (2010), carers and nurses also maintained conflicting
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23 views about seriousness of risk. Such divergence potentially supports concerns that the
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25 language of risk used by nurses differs from that of carers affecting the quality of any
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27 discussions (Clancy et al., 2014). However, some convergence between pre- and post- scores
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29 was evident in relation to self-harm which again matches other findings that carers place
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31 greater emphasis on service users' risk to self rather than risk to others (Coffey et al., 2017).
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33 Discussion in this area may have raised concerns for nurses or offered reassurance for carers
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35 demonstrating dialogue may be useful.
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40 This study was subject to the difficulties of delivering 'real world research' in busy healthcare
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42 and clinical environments (Gray, 2017). The difficulties encountered in this study could be
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44 attributed to a number of factors but are also likely to be relevant to the establishment of
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46 successful carer engagement strategies.
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50 Firstly, Ulrich et al., (2012) highlighted the competing tensions faced by nurses tasked with
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52 undertaking research whilst engaged in clinical practice. Likewise, despite recognising the
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54 importance and benefits of carer engagement, the nurses in this study appeared to struggle to
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56 prioritise the research, as although 41 members of nursing staff were trained, only 21 of them
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58 completed an intervention. There was also a marked difference in recruitment between the
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3 units. Local conditions, resources and priorities may have affected the likelihood nurses
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5 would participate as nurses on the unit completing the greatest number of interventions had a
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7 more stable staff group and generally a higher nurse to service user ratio. Therefore
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9 organisations serious about involving carers should therefore ensure services are adequately
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11 resourced if collaborative risk assessment and successful carer engagement strategies are to
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13 be achieved.
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17 Secondly, recruitment in the comparator group was undertaken in a systematic manner from
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19 clinical notes by the research team and less subject to selection bias. Whereas, for the
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21 intervention, nursing staff controlled access to eligible carers citing barriers including service
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23 user capacity and consent to involve carers. This is consistent with evidence suggesting
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25 nurses do not routinely reciprocate in information sharing (Rapaport et al., 2006), use
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27 confidentiality as a barrier, or withhold details about significant events or issues of safety
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29 (Gray et al., 2008). Nursing staff may have been more willing to recruit carers with whom
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31 they had existing positive working relationships or felt more at ease when faced competing
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33 demands for their time and energies (Cleary, 2004). Subject to such conditions, the sample
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35 recruited to participate in the intervention may be less likely to be disclosing new information
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37 to nurses in the dialogue and their existing satisfaction with the service could possibly be
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39 higher. Likewise, it is possible carers viewed by nurses as challenging or difficult were less
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41 likely to be recruited. They may have information not known to nurses or have less
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43 favourable perceptions of the service. The ways in which nurses can be supported to initiate
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45 and maintain contact with more challenging and difficult to reach carers warrants further
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47 enquiry. Although this study focused on discussions in relation to risk and service users
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49 safety, it has highlighted a number of issues relevant to how nurses communicate with and
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51 engage carers to exchange information more generally.
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3 Thirdly, operational changes within the organisation saw the GRIST replaced with another
4 risk assessment tool before the required number of interventions to provide meaningful
5 analysis was reached. Although the intervention could still have been delivered, it was
6 decided by the research team it was unlikely that pre- and post- discussion nursing scores
7 would be recorded, therefore recruitment ceased. The lack of evidence regarding the validity
8 and reliability of the GRIST must be acknowledged. In addition the Carer Experience Data
9 Capture Survey was not subject to robust testing and development.
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20 Finally, this was a small scale pragmatic study conducted with inpatient nurses and two
21 independent groups of carers within one service. Consequently findings are not necessarily
22 generalisable but may be of interest to similar settings and groups of carers.
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28 **Conclusion**

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31 In this study, carers who were engaged in a structured dialogue focused on risk reported
32 higher levels of satisfaction than those who were not. However, carer-nurse consensus
33 regarding the type and severity of risk was not achieved. Also, despite findings demonstrating
34 carers and nurses could come together discuss their concerns about the planning and
35 management of safety, **whether** or not communication actually takes place may be at the
36 discretion of the nurses rather than the right of the carer. Thus, there would be benefit in
37 finding ways to help nurses to navigate situations in which service users' rights for
38 confidentiality conflicted with a carer's right for support. Nurses should be encouraged to
39 engage proactively with all carers. Findings provide support for increasing carer contribution
40 in discussions regarding risk and suggest further work investigating the use of structured
41 approaches to embed carer involvement in clinical practice is warranted.
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57 **Ethics**

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3 Approval for the study was gained from the Yorkshire and Humber-South Yorkshire NRES
4 Committee 15/YH/0033. Participation was voluntary but had to be fluent in English. Written
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6 informed consent was obtained from service users and carers. Participants could withdraw
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8 their data from the research study up until the data had been prepared for publication.
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11 However new information relating to safety would be retained for the purposes of ongoing
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13 risk assessment by the service.
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17 18 Key points

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21 • Carers expressed increased satisfaction levels of satisfaction when engaged in a
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23 structured dialogue focussed upon risk and safety issues.
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27 • Although carers given the opportunity to discuss their concerns felt listened too,
28
29 neither carers nor nurses changed their views about which type of risk or what level of
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31 risk service users posed.
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35 • It is not clear what takes place when nurses and carers discuss risk. There is a need for further
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37 research to aid understanding about these interactions.
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41 • Further work to identify strategies to engage carers in discussions about service user
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43 safety are warranted.
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References

- Australian Government (2010) Carer Recognition Act 2010. Australia: Australian Government.
- Campbell A (2004) How was it for you? Families experiences of receiving Behavioural Family Therapy. *Journal of Psychiatric and Mental Health Nursing* 11(3): 261–267.
- Carers UK (2017) State of Caring 2017. London: Carers UK.
- Chatzidamianos G, Lobban F and Jones C (2015) A qualitative analysis of relatives', health professionals' and service users' views on the involvement in care of relatives in Bipolar Disorder. *BMC Psychiatry*, 15(1): 1-12.
- Clancy L, Happell B and Moxham L (2014) The Language of Risk: Common Understanding or Diverse Perspectives? *Issues in Mental Health Nursing*, 35(7): 551-557.
- Cleary M (2004) The realities of mental health nursing in acute inpatient environments. *International Journal of Mental Health Nursing* 13(1): 53-60.
- Coffey M, Cohen R, Faulkner A, Hannigan B, Simpson A and Barlow S. (2017) Ordinary risks and accepted fictions: how contrasting and competing priorities work in risk assessment and mental health care planning. *Health Expectations*, 20(3): 471-483.
- Cree L, Brooks H, Berzins K, Fraser C, Lovell K and Bee P (2015) Carers' experiences of involvement in care planning: a qualitative exploration of the facilitators and barriers to engagement with mental health services. *BMC Psychiatry* 15: 208.

1
2
3 Crombie I, Irvine L, Elliot L and Wallace H (2007) Carers of people with mental health
4 problems: Proposals embodied in current mental health policy in nine countries. *Journal of*
5
6
7
8 *Public Mental Health Policy* 28(4): 465-48.

9
10
11 Department of Health (2007) Best Practice in Managing Risk. London: DOH.

12
13
14 Department of Health (2010) Recognised, valued and supported: next steps for the Carers
15
16
17 Strategy. London: DOH.

18
19
20 Department of Health (2014) Information sharing and suicide prevention: Consensus
21
22
23 statement. London: DOH.

24
25
26 Farrelly S, Lester H, Rose D, Birchwood M, Marshall M, Waheed W and Thornicroft G
27
28 (2015) Improving therapeutic relationships: Joint crisis planning for individuals with
29
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psychotic disorders. *Qualitative Health Research* 25(12): 1637-1647.

Gee A, McGarty C and Banfield M (2016) Barriers to genuine consumer and carer
participation from the perspectives of Australian systemic mental health advocates. *Journal*
of Mental Health 25(3): 231-237.

Gilbert E, Adams A and Buckingham C (2011) Examining the relationship between risk
assessment and risk management in mental health, *Journal of Psychiatric and Mental Health*
Nursing 18(10): 862-868.

Gray, D. (2017) *Doing Research in the Real World* (4th ed). Sage, London.

Gray P, Robinson C, Seddon D and Roberts A (2008) 'Confidentiality smokescreens' and
carers for people with mental health problems: the perspectives of professionals. *Health and*
Social Care in the Community, 16(4): 378-387.

1
2
3 Happell B, Wilson K, Platania-Phung C and Stanton R (2016) Physical health and mental
4 illness: listening to the voice of carer, *Journal of Mental Health*, 26(2): 127-133.

5
6
7
8 James N (2016) Supporting carer during assessment and treatment unit admission. *Advances*
9 *in Mental Health and Intellectual Disabilities* 10(2): 116-127.

10
11
12
13
14 Littlechild B and Hawley C (2010) Risk assessments for mental health service users: Ethical,
15 valid and reliable? *Journal of Social Work* 9(4): 1-19.

16
17
18
19
20 National Patient Safety Agency (2009) Preventing suicide: A toolkit for mental health
21 services. NHS: National Reporting and Learning Service. London.

22
23
24
25 Rapaport J, Bellringer S, Pinfold V and Huxley P (2006) Carer and confidentiality in mental
26 health care. *Health and Social Care in the Community* 14(4): 357-365.

27
28
29
30
31 Ryan T (2002) Exploring the risk management strategies of informal carers of mental health
32 service users. *Journal of Mental Health* 11(1): 17-25.

33
34
35
36
37 Simpson A, Hannigan B, Coffey M, Jones A, Barlow S, Cohen R and Faulkner A (2016)
38 Cross-national comparative mixed-methods case study of recovery-focused mental health
39 care planning and co-ordination: Collaborative Care Planning Project (COCAPP). *Health*
40 *Services and Delivery Research* 4(5).

41
42
43
44
45
46
47 Substance Abuse and Mental Health Services Administration (SAMHSA) (2009) Family
48 psychoeducation: how to use the evidence-based practices KITs. Rockville, MD: US
49 Department of Health and Human Services.

50
51
52
53
54 Stanbridge, R., Burbach, F. & Leftwich, S. (2009) Establishing family inclusive acute
55 inpatient mental health services: a staff training programme in Somerset. *Journal of Family*
56 *Therapy* 31(2): 233-240.

1
2
3 Stanbridge R, Burbach F, Rapsey E, Leftwich S and McIver C (2013) Improving partnerships
4 with families and carers in in-patient mental health services for older people: a staff training
5 programme and family liaison service. *Journal of Family Therapy* 35(2): 176-197.
6
7

8
9
10 Ulrich C, Zhou Q, Ratcliffe S, Ye L, Grady C and Watkins-Bruner D (2012) Nurse
11 Practitioners' attitudes about cancer clinical trials and willingness to recommend research
12 participation. *Contemporary Clinical Trials* 33(1): 76 –84.
13
14
15

16
17
18 Worthington A, Rooney P and Hannan R (2013) *The Triangle of Care, Carers Included: A*
19 *Guide to Best Practice in Mental Health Care in England*. London: Carers Trust.
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**Carer Involvement in Risk Assessment:
Key worker/Carer Interview Recording Sheet**

Patient Label
Name:
NHS No:

Patient ID..... Consent form completed

Relationship of carer to patient Results requested

Please note: you should only answer the questions that you wish to do so

What 3 things relating to the service user concern you or keep you awake at night?

Which area of risk do these issues/concerns relate to?

- Vulnerability of service user Self-harm
- Self-neglect Harm to others/ damage to property
- Suicide Risk to dependents
- **Other areas of identified risk?**

Bearing in mind there are no right or wrong answers where would you place your family member/friend on the following scale in relation to:

SUICIDE

PRE DISCUSSION CARER SCORE



PRE DISCUSSION WORKER SCORE



Discussion

POST DISCUSSION CARER SCORE



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SELF-HARM

PRE DISCUSSION CARER SCORE



PRE DISCUSSION WORKER SCORE



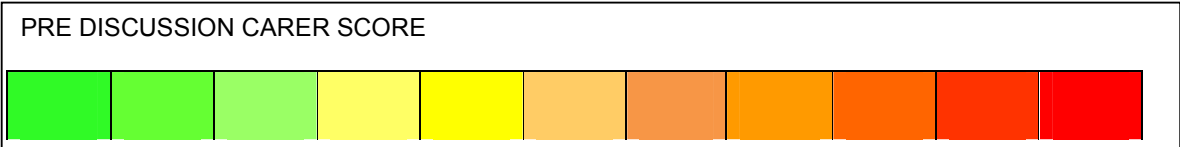
Discussion

POST DISCUSSION CARER SCORE



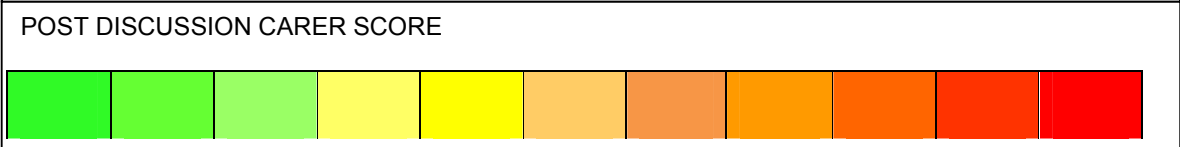
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HARM TO OTHERS/DAMAGE TO PROPERTY



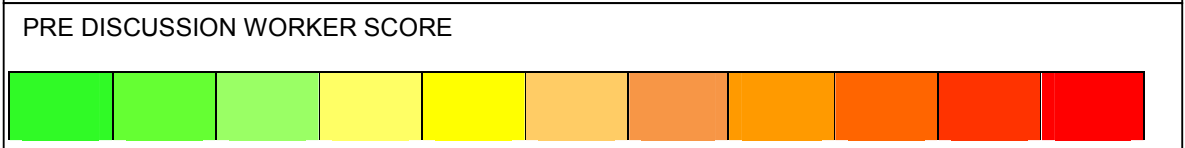
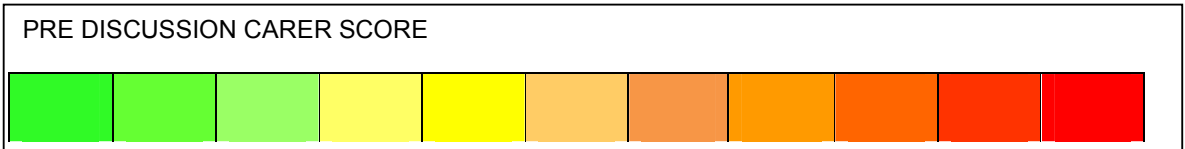
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A large, empty rectangular box with a thin black border, intended for a written discussion.

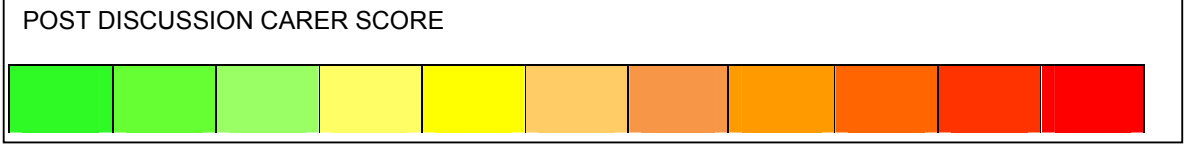


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SELF-NEGLECT



Discussion



RISK TO DEPENDENTS

PRE DISCUSSION CARER SCORE



PRE DISCUSSION WORKER SCORE



Discussion

POST DISCUSSION CARER SCORE



VULNERABILITY OF SERVICE USER

PRE DISCUSSION CARER SCORE



PRE DISCUSSION WORKER SCORE



Discussion

POST DISCUSSION CARER SCORE



Nurse (<i>print name</i>):		Designation:	
Date:		Signature:	
Carer (<i>print name</i>) <i>if applicable</i>		Relationship	
Date:		Signature	

RECORDING SHEET

Areas of risk identified on Grist	Pre-discussion	Staff	Post-discussion	
	carer score	worker score	carer score	worker score
Suicide	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Self-harm	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Harm to others or damage to property	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Self-harm	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Risk to dependents	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Vulnerability of Service User	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>



**Carer Involvement in Risk Assessment:
Carer Experience Data Capture Form**

Unit:

Client ID:

Consent to share information:

Please note you should only answer the questions that you wish to do so

1. Did you get the opportunity to say what you were worried about?

A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	Moderately <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
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2. Did the care team share what they were worried about?

A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	Moderately <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
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3. How involved did you feel in decisions made about risk?

A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	Moderately <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
-----------------------------------	---	--	--------------------------------------	--

4. How satisfied were you that they focussed on the right area of risk?

A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	Moderately <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
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5. How satisfied were you that the care team understood the severity of the risk?

A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	Moderately <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
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6. Overall how satisfied were you with the service?

A lot <input type="checkbox"/>	Quite a bit <input type="checkbox"/>	Moderately <input type="checkbox"/>	A little <input type="checkbox"/>	Not at all <input type="checkbox"/>
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