# Mapping the CNWL Trust-wide initiatives for relatives of people with mental health problems
## A Commissioned Independent Review

THE SPECTRUM CENTRE

## The Spectrum Centre for Mental Health Research

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# 1. <u>Introduction – Context</u>

Mental health carers play an important role in supporting both those they care for and the NHS as a whole. The number of those caring for a relative, partner or friend experiencing mental health problems ranges between 1.5 and 1.6 million (Arksey et al., 2002; Maher & Green, 2002). It has been estimated that the annual cost of all aspects of the NHS for the year 2009 to 2010 was approximately £98.8 billion, while the care provided by all carers across the U.K. is worth approximately £119 billion every year (Buckner & Yeandle, 2011). It has also been estimated that, for schizophrenia and psychosis alone, the unpaid services offered exclusively by the mental health carers would cost the NHS approximately £1.24 billion per year (The Schizophrenia Commission, 2012), while the cost of lost productivity of carers is £32 million and the cost of informal care and other related expenses which are covered by carers approximates £615 million (National Institute for Health and Clinical Excellence, 2010, p. 31). It is evident that that the services offered by carers play a pivotal role in sustaining both the healthcare system and society on the whole.

With the shift from prolonged hospitalisations to care in the community, carers' involvement has been brought in the forefront of healthcare provision and has been supported by numerous policies and regulations (HM Government UK, 1995, 2000, 2004; UK DoH, 1987, 1996, 1999, 2004a, 2004b, 2005, 2006, 2008, 2009, 2010). The NICE guidelines for schizophrenia (National Institute for Health and Clinical Excellence, 2010), for Bipolar Disorder (National Institute for Health and Clinical Excellence, 2006) and for people who self-harm (National Institute for Health and Clinical Excellence, 2004) also highlight the importance of carers' involvement.

The sheer volume of policies and regulations allows one to assume that the system has responded to the carers' needs in fulfilling their highly demanding role. The reality, however, is different. According to The Next Step for the Carers Strategy carers "need better and timely access to information; feel excluded by clinicians; find assessments overly bureaucratic and slow; feel forced to give up work to care; neglect their own health and need advice to maintain their well-being; feel that the rules

around overlapping benefits are unfair; and that more should be done to identify and support young carers" (UK DoH, 2010, p. 6).

Within this context the Central and North West London NHS Foundation Trust (CNWL thereafter) has invested on a series of initiatives over recent years that aim to improve the carers' experience. The Trust works to ensure that carers are provided with the necessary information and advice aiming to support their caring role. This includes specific information about support groups and information of partner organisations that are able to provide services in response to an identified carer need. The Trust also undertakes Carers' Assessments and makes formal referrals to other in house specialised services (e.g. Family Interventions), or services provided by partner organisations. Carers in the Trust's catchment area also have access to a number of services that are not provided by the Trust itself. These are offered primarily by local authorities, voluntary organisations or other non-statutory bodies. In partnership with such organisations, CNWL members of staff are also involved in co-facilitating carer support groups that are jointly funded. It is often the case that certain services are only available in specific boroughs.

## 2. Present Commissioned Independent Review

The present report is a CNWL commissioned independent review of some of the Trust wide initiatives provided or developed by the Trust in an attempt to map the services that carers currently receive or have access to, and the ways that these could be improved. The review is performed in the context of a research collaboration between the Trust and the Spectrum Centre for Mental Health Research, Lancaster University. The review aims to map the Trust wide initiatives that are related to carers of people with mental health problems, by addressing 3 questions. These are:

1. What is the Trust's formal position in relation to carers? Is 'carers' involvement' reflected in policy documents?
2. What services are available for carers?
3. How does the Trust assess the carers' experience?
   a. What do data from previous internal work suggest about the carers' journey?

# 3. <u>Methodology</u>

The author performed the review of a series of Trust wide initiatives by studying several internal reports (see list below). These have been selected and supplied to him by various members of CNWL staff. Emmi Honeybourne, a CNWL member of staff, provided summaries of some of the initiatives reviewed (Initiatives: 5, 6, 7, 8, 9, and 11 from the list below).

A list of the initiatives reviewed follows:

1. Service Users & Carers and the Care Programme Approach 2007 (Making the CPA work for you)
2. Care Programme Approach (CPA) POLICY (2009)
3. Annual Plan Review 2011-2012
4. Carers strategy 2012-2013
5. Carers Focus Group Outcomes (Oct/Nov 2012)
6. Think Family Report (2012)
7. Telephone Survey- Carer Experience of Crisis Services (Aug 2012)
8. Complaints Report- June 2012
9. Trust wide CNWL 2007 Carer's Survey (Nov 2007)
10. Themes from user experience surveys 2011-2012
11. Mystery Shopper board paper- Jan 2012
12. Recovery College

## 3.1 CNWL initiatives on carer involvement: a review

The review is organised into three sections. The first section discusses some of the key CNWL policy documents that set the benchmark of service provision. The second section reviews some of the research initiatives that have been conducted in the Trust that focus on carers. The third section focuses on other initiatives that the Trust has supported to either assess the carers' experience or support their involvement through training.

### Section 1: CNWL policy documents

### 1. <u>Service Users & Carers and the Care Programme Approach 2007 (Making the CPA work for you)</u>

**REVIEW:** This is a comprehensive report. Pages 33 to 35 in particular describe "What can carers expect from the CPA". The document provides a thorough description of what carers are entitled to

and how staff should meet carers' needs. It is evident that the intention to support carers in fulfilling their role is present. It is important to ensure that in order for the CPA to be implemented the continuous support of those involved (i.e. carers, health professional and service users) is a prerequisite.

## 2. Care Programme Approach (CPA) POLICY (2009)

**REVIEW:** This is a very detailed report that "sets out the framework for assessment, care planning, review, care co-ordination and service use and carer involvement underpinning the delivery of quality mental health services throughout Great Britain". Pages 41 to 46 in particular focus on identifying Carers, Carer Entitlements, Young Carers, Carers Assessments, Carers Support Plans, Service Users with Caring Responsibilities, Service Users with Dependent Children, Service Users Looking After Vulnerable Adults. Specifically, the report states that "Carers often provide the most consistent support for service users and can be essential in maintaining their health and wellbeing and promoting their recovery. Carers can make important contributions to care plans and assessments and should be fully involved wherever possible. Carer involvement should be agreed with services users as appropriate, if necessary with negotiation to clarify any information the service user does not wish to be disclosed. Caring can also be a demanding role and this should be acknowledged by professionals" (p. 41). It is evident in this extract that the CPA acknowledges the contribution that carers make to the overall mental healthcare provision. The extract also encourages that carer involvement should be agreed with the service users *as appropriate*. It would be beneficial to all parties involved that 'as appropriate' is clarified so that any possible misunderstandings can be avoided. 'As appropriate' allows several interpretations (e.g. 'in the case in which it is appropriate', 'if and to the extent suitable to the situation', vs. 'as a matter of course', 'because it is required', 'as needed'), which could potentially lead to confusion in relation to the ways that the CPA can be operationalized by the health professionals. In effect, implementing what is described in this policy is dependent on the individuals involved. It would be important, however, that carers are provided with a copy of this document or a simplified summary of the relevant to

them sections so that they are familiar with what they should expect from the service (if this is not already the case).

## 3. Annual Plan Review 2011-2012

**REVIEW:** The Trust's commitment to the involvement of carers is reflected in the Annual Plan Review. It is clearly stated that one of the Trust's values is "Empowerment", under which it is specifically stated that: "We will involve people in their care plan and treatment, working closely with them, **their carers and families** to create practical solutions that meet individual needs. We will give our staff the support they need to grow and develop". Further, one of the Strategic Objectives of the Trust is the **meaningful engagement with carers**. Taken together, these statements set the framework that CNWL intends to operate. It is evident that the carers' needs for support are acknowledged.

The Annual Plan Review shows commitment to support the staff with the view to meet their needs. This is promising. What needs to be clarified, however, is the mechanism by which the Trust identifies staff needs and how these are addressed. Are there formal mechanisms which foster continuous and effective communication between staff and the Trust?

## 4. Carers Strategy 2012-213

The Trust's Carer Strategy for 2012-2013, including the 10 Standards, is outlined below:

"We recognise the important role of a Carer and will work to ensure that our services recognise the importance of family and friends in a person's care and recovery.

**The Standards**

These standards, developed through consultation, set out what carers can expect from our services and which we will work to attain.

**Information for Carers**

Standard 1:     Carers' should be provided with clear and up-to-date information and advice about Trust and other services, including local voluntary services and Carer Centres.

Standard 2:     Carers should be provided with information on how to access services and who to contact in times of emergencies and crisis.

Standard 3:     Each service should be able to provide standard material to carers about conditions, treatments and possible effects of medication.

Standard 4:     Services should be able to make information available in a format to meet the carer's needs or, alternatively, make individual arrangements to meet that need, for example through the use of an interpreter service.

**Responding to Carers' needs**

Standard 5:     Carers' should be treated with understanding and respect and taken seriously when expressing concerns.

Standard 6:     In all services we will work to promote carers' awareness of their entitlements to an assessment of their own needs.

**Carer involvement in the care and discharge planning**

Standard 7:     Carers' should be actively involved in the discharge and care planning for the person they support and informed of and invited to attend the CPA / care planning review meetings, with his/her consent.

**Carers' involvement in the planning and development of Trust services**

Standard 8:     We will work to promote and increase Carer involvement in Trust activities which influence decision-making in the planning and delivery of services.

Standard 9:     We will continue to improve the use of information from systems which feed back carers' views e.g. complaints, PALS, Trust carer focus groups, carer forums and carer interface meetings.

**Development of CNWL Staff**

Standard 10:   We will continue to work to raise staff awareness and knowledge of issues affecting carers, for example through optimising opportunities in training, working in partnership with Carer Centres, and through the Recovery College.
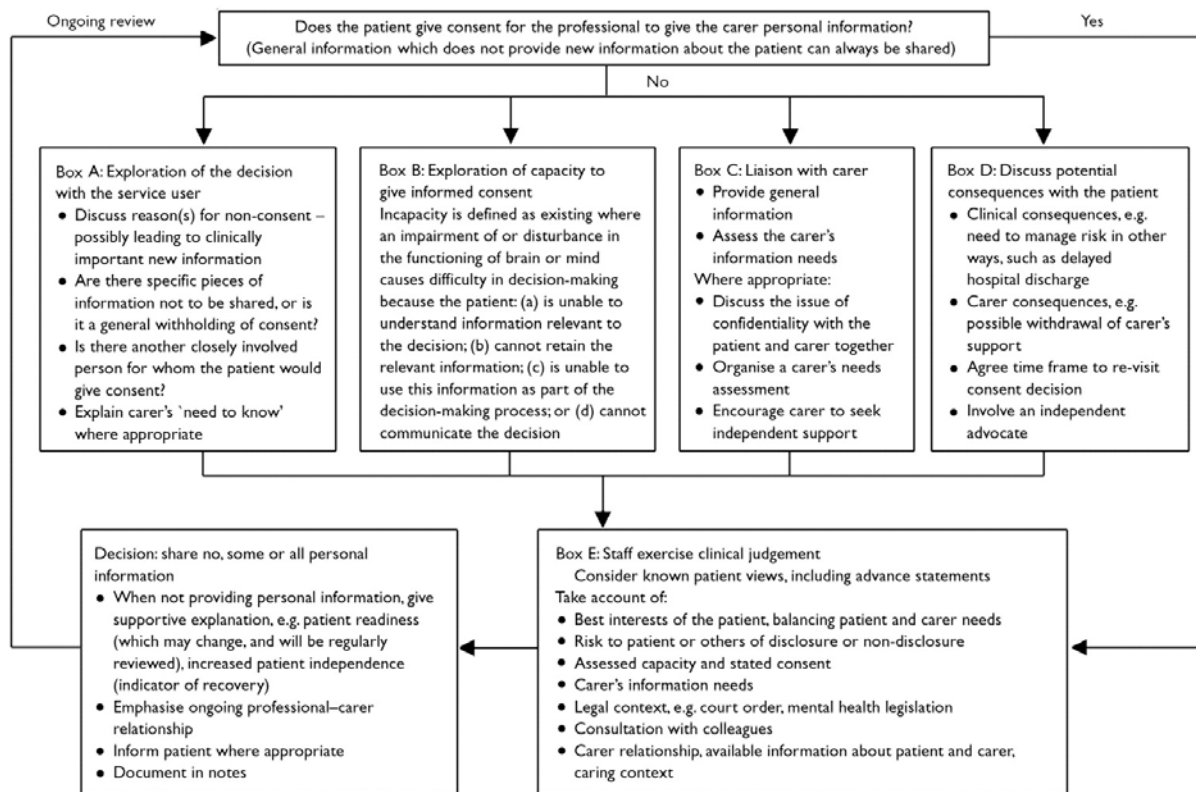
**Carers**

*Carers may be partners, parents, children or other family members, or friends. Carers may or may not be living with the person they support, and often provide support on an ongoing daily basis. Where someone is identified as a carer, by the person using services, or by people providing services, they are legally entitled to be told of their right to a carer's assessment, even if the person they care for refuses to engage with services themselves. Carers are not always advocates for people who use services though they can be. Carers are not paid for providing this support and are not care workers, support workers or people supporting someone as a volunteer or paid through personal budgets.*

*Revised from:  Carers' Involvement Strategy (June 2004) and Trust Carer Standards (online)"*

**REVIEW:** This is a comprehensive list of what carers should expect from the services, which highlights the emphasis that the Trust places in supporting this group. As before, and in addition to formal support of all involved, an equally clear operational framework is required that provides step by step guidance of how to put these standards into practice. It would be highly beneficial for CNWL

members of staff to receive guidance and/or training of how to apply Standard 7 when a service user does not consent in their carers being involved. Obtaining SUs' consent is of critical importance as it is both a legal requirement and a clinical ethical principle. Slade et al. (2007) provides a comprehensive framework of how mental health staff can address this challenge in the clinical practice (see Figure 1).



**Figure 1. Framework for best clinical practice when consent is not given to share information with carer (adopted from Slade et al., 2007)**

## Section 2: Research Activities

1. **Carers Focus Group Outcomes (Oct/Nov 2012)**
   - Focus groups run in order to hear from carers (across all service lines) about their experiences of services. This was an extension of the Carer Telephone Survey work (April 2012).
   - The views of 31 in depth qualitative information were grouped under 5 themes (see Table 1).

| Theme generated by Carers | Subsequent Action Taken |
|---|---|
| More general info needed about services. | Service lines developing general information leaflets about service/team/ward to be given to SU's, family and carers. |
| More info needed about how to access services when you were concerned about a family member. | Information developed around how to access services in times of concern. 'Carer Contact Cards' developed with telephone numbers. |
| Not always clear who to call 'out of hours'. | Urgent Advice Line (out of hours) has been launched. |
| Services need to recognise the role of carers in supporting SU's. | 'Family inclusive practice' is in development across the trust. Including: improving identification of carers, focus groups, improved recording of carer involvement, staff training. |
| There should be greater family involvement in care planning. | '8 steps' poster on 'Information Sharing with Carers' has been re-launched across services supported by carer interface meetings, focus groups, and staff training. |

**Table 1. Focus Groups Themes and Actions Taken**

**Further Trust Developments based on outcomes:**

'Recovery College'

- Carers recruited to become 'peer trainers', co-producing and delivering courses for other carers.

'Carers Council'

- Trust carer council established and chaired by a carer governor. Council will monitor progress on carer developments. Representing all service lines.

**REVIEW:** Exploring people's views by conducting focus groups is an appropriate qualitative methodology to identify collective attributions and attitudes, experiences and approaches, or beliefs. In effect, focus groups can provide a very meaningful methodology in studies that aim to inform policy making. Conducting focus groups is highly demanding and results are often dependent on the moderator's skills to extract quality data and on the dynamic of the people who take part. As such, a sound methodology of delivering focus groups is very important so that quality data can be collected.

The limited available information on the methodology of the focus groups described in this report restricts the possibility for a full review of the results. From the data being available, however, it becomes apparent that different numbers of people attended each focus group. In fact, the Hidden Carers focus group was attended by 1 participant (see table 1).

| Groups | Participants |
|---|---|
| Learning Disability | 5 |
| Hidden Carers | 1 |
| Adult Carers | 3 |
| BME Carers | 13 |
| OPHA | 3 |
| Young Carers | 7 |
| Total | 31 |

**Table 2. Number of participants per focus group (adopted from Halsted, A. 2012. Carer CQUIN Focus Group Outcomes, CNWL, pg. 1)**

Also, the groups themselves appear to be intrinsically different from one another. These two facts make the results hard to interpret in a meaningful way. Further, when results of such diverse groups need to be fused to a single cohesive piece of work that would be applicable across the Trust, the analyst is likely to remain at the surface of the topics being discussed.

Additional information necessary to conduct a more comprehensive review of this initiative would include:

1. How representative are the participants of the broader population of relatives? To what extent can their views be generalised to other relatives?
2. The types of participants. How well informed were they about the rationale of the focus groups? How homogeneous were they as a group? Any other demographic information available? Did participants receive any payment to take part? How were they invited to take part?
3. What were the topics being discussed?
4. What was the role of the moderator? Was this the same person across all of the focus groups? Was there more than one moderator per group? What was the degree of control and direction imposed by moderators?

While these focus groups attempted to address a very important question, without any information from the issues listed above any results should be treated with caution.

## 2. Think Family Report (2012)

- Social Care Institute for Excellence recommendations: need for services to develop ways to involve 'family members'.
- Engaging patients' relatives is in line with the 'Recovery Approach'.
- Objective of this audit- to capture a snapshot of good practice and service gaps.
- Questionnaire circulated to health care professionals across all service lines (Learning Disabilities, Crisis Resolution Team, Acute, Psychological Medicine, Older People/Healthy Aging, CAMHS, Offender Care, Eating Disorders, Addictions, Rehab, ABT):

    1) How does the Think Family (TF) Approach feature in your service lines' clinical model?
    2) Given your patient group, how is this delivered in terms of clinical practice?
    3) Are there ways to capture this activity to evidence it is being delivered?
    4) What training, consultation, supervision is provided to promote a TF approach in your Service Line? b) Is it effective? c) If it is not accessible what would complement the skill mix of your workforce?
    5) What would enable your Service Line to build on current good practice to further imbed a TF approach?

- Themes emerging from Audit:
    - ➢ Considerable support for the approach but delivering it effectively requires assistance.
    - ➢ Think Family approaches need to be adapted to suit patient groups and patient needs.
    - ➢ IT solutions must be developed to record the TF approach and carer involvement.
    - ➢ Ways to embed learning from training into practice required.

- Current Initiatives within Trust to better meet needs of patients and their caring system:
    - ➢ CAMHS training programme on family involvement
    - ➢ Nursing directorate reviewing arrangements with external providers of Family Focused Training.
    - ➢ Initiatives to strengthen position of Carer involvement: Carers Council

**Review:** This is an important initiative that highlights the significant role of relatives in the clinical practice. What is also important is the fact that the report puts emphasis on the operational aspects of delivering the TF approach, acknowledging this way that this is an area that needs to be supported. It is evident that the Trust has engaged into initiatives with the view to improve the standards of care delivered. Relevant descriptions of the methodology by which this audit was conducted would help built an evidence base of how internal research is conducted, of effective mechanisms of collecting data, and of possibilities for improvement. A key question is around who the survey was sent to and who responded. This would help understand how representative the staff responses were.  Also, despite the fact that the emergent themes are consistent with current literature on the area, it is unclear how these were elicited or how much they were inevitable

responses of the questions been asked (i.e. the difference between reporting primary coding as themes vs. reporting the emergent data synthesis product). Further work could be based on the findings of this report to address new questions. For example:

- **Theme 1**: What type(s) of assistance would enable the application of the TF approach in the clinical practice? Who should offer the assistance, who needs help, and for how long?

- **Theme 2**: For the TF approach to be adapted for specific patient groups and patient needs, both the groups and the needs have to be identified first. This would require individual research projects that focus on each Service Line in isolation, so that meaningful data for each patient group can be generated. Results from these projects can then be fused together with the view to develop a Trust wide TF strategic planning.

- **Theme 3**: It is important to identify ways by which relatives' involvement is operationalized, monitored and recorded accurately and appropriately. What process measures are in place that would enable a member of staff to record contacts with relatives? Despite the risk of increasing bureaucracy, the focus of such initiatives should be the development of the structures that would enable members of staff to record their work, based on which good practice can be acknowledged, rewarded, and incentivised. Without such work, existing FT practices which may have been of high standard may remain unnoticed.

- **Theme 4:** This is a common research finding; training is not always reflected in people's practice. The finding, however, provides the basis for further questions to be addressed. What support is available for staff that enables them to apply the recently acquired knowledge? Is clinical or peer supervision available? Any other type of support they need? Training is often based on textbook cases that refer to utopic or unrealistically straightforward circumstances, which cannot be easily applicable to the reality of a ward. The involvement of service users and carers in consultation, joint training with professionals, user led training, curriculum development and quality assessment has been found to increase the effectiveness of training programmes (Wallcraft et al., 2011).

3.  <u>Carer Experience of Crisis Services – Carer CQUIN Telephone Results (August 2012)</u>

- In Feb and April 2012, two telephone surveys conducted to establish whether Carers' felt supported by staff in their involvement in crisis planning.
- 137 responses from carers
- Quantitative survey included questions about involvement in care planning and crisis planning, followed by 'what 3 things would have made your experience better?'
- 74% reported being given information of what to do in a crisis
- 52% reported being involved in developing the crisis plan
- 64% reported staff generally listened to their concerns about the person they cared for.
- 82% of carers stated they have been involved in the care planning of the person they are supporting.
- Carers reported '*being listened to'*, 'being *involved in care planning*' and '*being given crisis numbers to call'* were three things that would have improved their experience.
- No comparison across boroughs.

**Review:** This is yet another very important initiative that indicates the emphasis that the Trust places upon relatives' experiences. However, specific methodological problems make the interpretation of the findings difficult. First, it is unclear whether the expected total number of carers in the Trust is known. This is an important figure in order to capture an accurate response rate, which in effect will allow the interpretation and generalizability of the findings. The report describes results based on a response rate in relation to the number of questionnaires sent out (i.e. 312) and not of the total number of carers who should have received the questionnaire. The total number of carers seems to have been identified by requesting names and telephone numbers from team managers, while CNWL personnel seem to have worked with a series of Carer Centres to raise awareness of the study. As acknowledged by the authors of the Telephone Survey, given the size of the Trust's catchment area, the total number of carers identified is too small to allow for reliable comparisons or predictions. Also, it is unclear how the 137 carers who did respond to the survey would compare to the remaining 175 who did not. How would their answers have been likely to differ? These are some questions that would enable the understanding of the sample of a study. In the absence of such information it is very likely that the results reported here are based on a biased sample.

Also, while the 43.9% response rate may seem reasonable compared to other similar research, based on the NIHR 2009 Surveys and Questionnaires report the "worst case scenario" should be assumed at 50% response rate (Mathers, Fox, & Hunn, 2009, p. 16). Applying the NIHR calculations onto this

survey, the 137 respondents lead to a margin of error between 8% and 10%. A margin of error is a statistic that is used in survey's results to indicate the amount of random sampling error. The larger the figure, the more likely that the survey's reported results are not expressing a "true" representation of the whole population. Margin of error occurs whenever a population is incompletely sampled. This 8% to 10% margin of error signifies incomplete sample and warrants caution when interpreting the results.

While there are pragmatic difficulties in identifying this hard to reach sample, it is important to establish a database of carers. This would provide great opportunities to conduct research with this group, but would also allow the Trust to strategically reach this population, develop and accurately budget the support that would help carers fulfilling their role.

Overall, the data on relatives' satisfaction reported here sketch a more positive picture than what has previously been reported (Pinfold & Corry, 2003). It is hoped that at least some of this can be accounted for by an improvement of service provision over the years. However, two more explanations could shed light to the findings. First, services in CNWL are indeed responsive to relatives' needs and this is reflected on the data. Second, the sample who responded in the questionnaire was skewed. Given the small sample size it is hard to conclude which of the two explanations is most accurate. What is evident is that there is a need for the Trust to develop mechanisms to record the exact number of carers that receive or should have access to carer's support.

## 4. Complaints Report- June 2012
- 61% of complaints made by service users concerned with their own care, 39% raised by either a relative, carer, friend, advocate or solicitor.
- Key issues for complainants: aspects of clinical care, staff behaviour and communication. Complaints by service users similar to those raised by others on their behalf.
- Carer-specific outcomes/developments following complaints:
  - ➢ Need for on-going awareness raising with staff, of the importance of good verbal communication and customer care
  - ➢ Need for improvement in interaction between carers and staff, around info about leave, transfer, updating concerned relatives.
  - ➢ Need to improve on communication with relatives in terms of respect and empathy.

**REVIEW:** This is a very comprehensive report, which includes a large body of statistics on complaints received in the Trust. The results may be used to draw attention to specific areas that require further consideration. No data that are exclusively related to carers' complaints are available. Carers are included in the general 'third parties' sources of complaints which consists of relatives, friends, advocates and solicitors. It is assumed that the nature of a complaint by an unpaid carer would be qualitatively different to complaints made by solicitors. For the purpose of this review, and under the more general aim to improve the carers' journey, it would be beneficial to identify complaints that have been made from carers with the view to identify the challenges they face in their attempt to access services for the people they care for and for themselves.

## 5. Trust wide CNWL 2007 Carer's Survey (Nov 2007)

- Questionnaire developed to get a picture of carer involvement and support within the Trust.
- Managers of adult services (CMHT's, early intervention services, community outreach and assertive outreach) asked to identify 20 known carers. Total of 493 questionnaires sent out across boroughs and **83** were returned (i.e. 17% return).
- Questions included:
  - ➢ details of caring role (length of time, caring for whom?)
  - ➢ whether the carer receives any practical or emotional support
  - ➢ what sort of support the carer feels they provide to the person they are caring for
  - ➢ what information they have been given by the trust
  - ➢ what support they are currently accessing (including whether or not they have had a carers assessment)
  - ➢ involvement in care planning, involvement in crisis planning
  - ➢ carer demographics

- Based on quantitative outcomes, a number of priorities outlined for Trust:
  - ➢ Identifying 'hidden' carers- all service users screened to identify carers
  - ➢ Carer information packs developed
  - ➢ CPA policy: all identified carers should be informed of their legal right to an assessment of their needs. Carers involvement acknowledged and described in service user care plans
  - ➢ All carer given information about their relatives condition and treatment, told who to contact in an emergency, given 'out of hours' support info, given a copy of SU's CPA.
  - ➢ Carers invited to CPA review meetings
  - ➢ A three year strategy is to be developed to take forward the development of Carers' Assessments, carer recognition, information provision and carer involvement in planning.

**REVIEW:** This was an ambitious study that aimed to create a Trust-wide baseline around carers' experience, with a large volume of data been collected. These, however, derive from a comparably very small sample. Only 17% of the questionnaires sent out were returned. This figure in relation to

the Trust's catchment area, number of people on caseloads, and the diverse services offered lead to difficulties in interpreting the findings in a meaningful way. Similar methodological issues with the Telephone Survey discussed earlier also appear here. It is evident that new mechanisms are needed that would enable the identification of carers in effective and useful ways.

## 6. Themes from user experience surveys 2011-2012

- This was a paper that aimed to provide an analysis of the results of various User Experience surveys conducted Trust wide during 2011/12. The surveys included were
  i. The National Surveys of Mental Health Patients conducted for 2010 (In-patients) and 2011 (community)
  ii. Quarterly service user-led telephone surveys of people who have been seen within the in-patient and community adult and older adult services.
  iii. A six-monthly face to face survey of current inpatients in the adult and older adult acute admission wards across the Trust, including PICU's, conducted by The Service User Survey Team.
- The results were presented in the form of themes.
- Discussion of the Trust's progress
- Feedback from service users was included

**Review:** While the aim of this paper was to provide the results of a series of initiatives around user experience, the report has no available descriptors of methodology by which the themes emerged. Also, it seems that the authors collated the data from various sources. When such methods are utilised it is important to describe:

a. What hypotheses did this report aimed to address?
b. What were the criteria based on which the surveys were included?
c. What methods were used in the surveys?
d. Descriptors of the sample of these surveys.
e. Were the surveys comparable? How?
f. What were the differences between the surveys analysed?
g. How were the analysed and reported data extracted from the surveys?
h. What model of analysis was used? (e.g. meta-analysis, narrative synthesis)

Without such information available a review is not possible.

# Section 3: Other Initiatives

## 1. Mystery Shopper Board Paper- Jan 2012

- Carers recruited as mystery shoppers during their visits to patients on the wards and residential units. Invitation to foundation trust members.
- Focus of the mystery shopping expeditions- to test the degree to which CNWL staff responds to the enquiries made by the shoppers, providing appropriate information and advice, and in the case of reception areas to make observations on access, signage and the availability of information in the form of leaflets and posters.
- To try to get a perspective of the experiences and observations of "real" carers when visiting relatives and friends in the inpatient services. A concern often cited by carers is that they do not receive a very welcoming response when they go to visit on inpatient wards, and are often not provided with sufficient information.
- Detailed data are provided below:
  - The mystery shopper team managed to recruit a total of 22 carers to undertake a role of mystery shopping while visiting their friends and relatives in residential care. These visits took place over 8 sites. The volume of visits per site ranged from 8 on one site to 1 each on 3 sites. The volume of visits in total is small and some caution is needed in analysing the results on the basis of percentage scores, however the results and the additional comments provided by carers give some indications of where improvements could be made. There was a variance of responses from carers about their experiences ranging from excellent to poor.
  - The majority (68%) of carers were female and white (73%), although there was an even spread of carers across the Black, Asian and Other ethnicity groups.
  - 100% of carers reported that they had no difficulties in getting to see the person they wanted to visit. One carer reported some difficulties in parking.
  - 91% of carers reported that they were made to feel welcome on the ward, however 2 (9%) did not experience their welcome at all positively.
  - 19 of the 22 carers (86%) reported that there was a suitable place for them to make their visit in private
  - Only 10 (45%) said that the ward staff introduced themselves to the carers, although a further 5 (23%) said this was not necessary as they were already known. However this still left 7 (32%) who had not been introduced to staff.
  - 90% of the carers said that the ward staff were available for them to talk to, and 77% said the ward staff were approachable and easy to talk to
  - Only 7 (33%) of the carers were able to talk to the patient's named nurse, although a further 9 (43%) said they did not need to talk to the named nurse.
  - 13 (62%) carers reported that ward staff answered any questions they had to their satisfaction and 4 (19%) did not ask any questions.
  - 9 (41%) of the carers reported that staff asked them questions about the patient, leaving 13 (59%) who were not able to share their information.
  - 91% of carers felt safe on the ward
  - Only 45% were invited to attend a care planning meeting
  - Only 41% saw or were offered any information that might be relevant to them e.g. visiting times, support services for carers
  - Carers key finding: visiting times are a missed opportunity for ward staff to share information with carers and to engage with them as key elements of the care team. Carers want to be engaged but are often not acknowledged for the support they provide to patients, and they need to be supported in this role. Working with carers on acute wards has been identified as a key objective in some hospital units.

**REVIEW**: 'Mystery shopping' is a well-established method to identify ways by which a service can be improved. This initiative is yet another indication of the Trust's commitment in assessing and improving the services on offer. The report includes some data that show that carers are consistently pleased by the facilities on offer and experience a sense of safety on the ward. However, there are some figures that are collectively difficult to interpret. For instance, 90% of carers appear to have been able to talk to staff (with 77% of the latter being approachable), but only 33% of carers were in fact able to talk to the named nurse of the person they care for – yet 62% of them reported that staff answered questions. There are also other data that contradict previous internal findings. For instance, the Telephone Survey reported 82% of carers being involved in the care planning of the person they are supporting. Here the similar statistic is almost halved (45%). This incongruence could be attributed to a number of reasons, some of which may be the methodology employed in the telephone survey, the small sample size that the authors of the Mystery Shopping acknowledge, or both. The result could also be attributed to the exact group of people who took part (i.e. skewed sampling), or the fact that data in the Mystery Shopper and the Telephone Survey come from different settings. This is particularly relevant to CNWL, given the size of the Trust's catchment area, and the fact that different boroughs offer different services. As such, similar future initiatives should ensure representative sampling from different boroughs, and service lines. Overall, however, the key messages are in agreement with the existing literature in relation to carers' experiences. Given the methodological issues, however, it is challenging to confidently link the conclusions with the data.

## 2. Recovery College

**REVIEW:** Established within the Implementing Recovery through Organisational Change Programme (ImROC), the CNWL is a pilot site for the delivery of a Recovery College (http://www.centreformentalhealth.org.uk/recovery/supporting_recovery_sites.aspx). This is a great initiative that aims to "offer support for people who use CNWL mental health services, and enable them to become experts in their own self-care", but also to "Enable family, friends, carers and CNWL staff to better understand mental health conditions and support people in their personal recovery

journeys". The CNWL Recovery College can potentially provide the educational avenue by which the Trust makes real impact to the increase of understanding of mental health conditions amongst staff, service users, carers and members of the public. With the way that people conceptualise 'Confidentiality' appearing to be a frequent barrier to carers' involvement, the curriculum could be enriched with specialised training on confidentiality, what it means, and how to use it in the clinical practice. A module on Confidentiality would be relevant to staff, carers and service users. It would also be interesting to see research based on the CNWL Recovery College data that focuses on the effects of education upon clinical practice, if any.

## 4. Discussion – Where does the CNWL currently stand?

The present independent commissioned review was set to map the Trust's current initiatives that regard carers and how these are (or are not) supported by the Trust's policy document. An integral part of the review focuses on how the Trust assesses the carers' experience and what services are currently available that carers of people with mental health problems have access to.

Prior to discussing these further, it is important to note two limitations of this review. First, only specific Trust wide initiatives were under review, which means that other local initiatives may also be present. The selection of initiatives reflected the Trust's development of work with carers over the past 6 years and included a variety of reports, actions plans, audits, as well as quality reports, complaints and incidents reports. Also, the information made available was based on the Trust's confidentiality policy to protect service users and carers. Second, this selection was performed by CNWL members of staff and not an independent party, on the basis that a person who is not employed by the Trust would not have been in a position to do so for obvious reasons.

Through the review of the documents described here, and other informal discussions with CNWL members of staff, it becomes very apparent that the Trust has invested in a series of initiatives that are aimed at providing support for carers. Some of these offer services in partnership with local authorities and other non-statutory organisations, and others are exclusively delivered by the Trust.

Support for carers which comes directly from the Trust is available during admission, discharge and treatment. This can take the form of provision of information and advice, signposting to other services available (usually offered by local authorities and non-statutory organisations), and formal referrals to family interventions services, or other external specialised services as and when necessary. The Trust also performs Carers Assessments in partnership with local authorities and co-facilitates the delivery of carer support groups for adult mental health service users, dementia, eating disorders and addictions. The Trust's commitment to the improvement of the carers' journey is also reflected by the fact that specific initiatives developed in house appeared in the first edition of the Triangle of Care report (Worthington & Rooney, 2010). Finally, the Carer CQUINs context within which this review is conducted is a strong indication that the Trust is keen to support research initiatives that aims to evaluate how carers experience the services they receive.

The discussion below is organised in accordance with the sections of the review.

**Section 1: CNWL policy documents**

Through the 4 documents that were reviewed, it becomes clear that the Trust acknowledges the importance of the role that carers have in the healthcare provision and that it is committed to the continuous improvement of the care provided to both carers and service users. The existence of these policies is a positive step towards collaborative care in mental health service provision. While carers' involvement is not immediately obvious in the development of these policies, it is imperative for similarly comprehensive documents to be developed that will provide step by step guidance and support of how to put these policies into practice. Carers' involvement in the development of these operational frameworks is considered a standard practice (and is supported by the existing policies).

**Section 2: Research Activities**

Six research activities were reviewed. Consistent with the intentions and commitment of the Trust to improve the standards of care relatives of people with mental health problems receive, it is evident that the Trust *cares about carers*.

Two major and frequent difficulties, however, are i) the limited available information on the methodology used to conduct these research projects, and ii) other specific limitations that are related to the design of these projects. As described earlier, both of these difficulties challenge the conclusive interpretation of the results in a meaningful way.

Based on the 6 research activities being reviewed, the total number of people who provide care for their loved ones is unknown. This is a major infrastructure gap, which warrants the development of a Carers' Database. The development of a Carers' database would enable:

- The identification of the total number carers, but also the identification of individual carers for follow ups
- The support of empirical research on carers' experience across the Trust (which in effect facilitate funds allocation)
- More rigorous comparative analysis between service lines and Boroughs
- The establishment of a channel by which carers and the Trust could communicate and exchange information
- The Trust to identify who these people are and their needs so that customised interventions for support can be informed
- Contacting only the people who want to be contacted
- Storage of data in a structured manner (minimise data repetition)

It is certain that the list above is not exhaustive, but knowing who the carers are is fundamental to both involving them in the development of services, and to providing to them the support they need, as opposed to what is thought to be effective for them. A Carers' database would allow the collection of high quality data that can be used across different operational sectors of the Trust – from policy development, to clinical practice and finance. Given the fact that this is an objectively hard to reach population, collecting the data could be challenging, especially due to the fact that who carers for whom may change over time, or because some carers may object to the idea of being identified with this role or even labelled as such.

On the basis that carers are entitled to services that are pertinent to their own well-being, which is often compromised by their caring role, the data collected should only be relevant to the types of information that carers would be interested in and other basic sociodemographics. The database should be built in ways that communication and data exchange with existing databases in the Trust

would be possible. This is particularly important for cases where a carer is also a service user. The IT department of the Trust in collaboration with the Information Governance Teams would be in a position to provide consultation on how such a database can be developed while ensuring that service user and carer data protection is not violated.

**Section 3: Other initiatives**

Two initiatives were reviewed. These were the Mystery shopper and the Recovery College. While the Mystery Shopper paradigm is well-established in identifying ways that services can be improved, the limited number of people who took part coupled with the contradictory data that were produced by other CNWL research increases the difficulty in interpreting the results. It is important, however, to repeat this exercise. Future Mystery Shopper initiatives should collect more data from all service lines and boroughs (when possible).

The Recovery College, on the other hand, provides a unique opportunity for a plethora of educational and research initiatives to be delivered. CWNL staff should be encouraged to attend relevant courses. The same applies to carers and service users. As described above, a series of courses on Confidentiality and its relation to carers' involvement would add to the curriculum greatly. The Recovery College can also be the ideal mechanism which supports other initiatives that raise awareness of the issues that carers face on a daily basis.

# 5. <u>Conclusion – Future work</u>

This independent commissioned review was conducted in the context of a collaboration between the CNWL and the Spectrum Centre for Mental Health Research, under the aegis of Trust's Carer CQUINs. Certain Trust wide initiatives were reviewed. Overall, it is evident that the Trust has supported a variety of systems and other developments that aim to improve the carers' experiences. These initiatives are consistent with good practice guidelines as outlined in the Triangle of Care agenda.

However, the review identified infrastructure gaps that may often lead to limitations that compromise the quality of the data being generated by several of the research activities. Further, the data reviewed here show that the Trust formally supports carers' involvement. However, while the Trust's intentions to involve carers are evident by its commitment as expressed in the policy documents, some of the available data show that the intentions are not always reflected by the ways that carers experience the services they receive. Challenges to implementing guidelines and policies have previously been identified (Francke, Smit, de Veer, & Mistiaen, 2008). In fact, out of 41 studies that explored the implementation of clinical guidelines in mental healthcare, guideline adherence was found in 27% of the cross-sectional and pre-post studies and in 67% of the controlled trials under review (Bauer, 2002). In some cases, guidelines contradict one another, whilst in others the reality of clinical practice does not allow staff to follow what they have been trained to or would have preferred to do. Future research projects should explore the barriers to implementing guidelines as experienced by the staff. Qualitative interviews conducted by independent researchers should focus on systematically exploring the experiences of members of staff from different service lines and Boroughs in their attempts to implement clinical guidelines that are relevant to carers. Such projects would also help develop mechanisms by which members of staff are able to anonymously communicate the challenges they face in their day to day practice, which may underlie some of the barriers to implementing guidelines. Table 3, below, summarises the proposed recommendations organised by the relevant review sections.

| Section 1: CNWL policy documents | • Development of step by step guidance and support of how to put the existing policies into practice.<br>• Carers should be involved in the development of these documents. |
|---|---|
| Section 2: Research Activities | • Development of a Carers' Database<br>• Improve sampling strategies on research studies<br>• New research: What are the barriers and the facilitators to implementing guidelines as experienced by members of staff? |
| Section 3: Other Initiatives | • Improve sampling strategies on research studies (Mystery shopper)<br>• Run courses on Confidentiality (Recovery College)<br>• Collect data on the effects of education upon clinical practice (for professionals), care delivery (for carers), and wellbeing (for service users & carers), if any. |

**Table 3. Independent Commissioned Report Summary Recommendations.**

Finally, at a local level, the Trust's Board along with the clinical and service leads may wish to use the evidence presented here to inform the development of collaborative approaches to mental health and wellbeing services across the Trust.

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