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Exploring the Impact of a Clinical Decision Support Tool from the Perspective of Service Users & Carers

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Abstract

This study was part of an evaluation of a Clinical Decision Support Tool (CDST) which was developed as the basis for the Integrated Packages Approach to Care (InPac) model for adult mental health services in South West Yorkshire Mental Health NHS Trust (SWYMHT). The study investigated the use of the CDST and its potential impact on service users and carers through the standardisation of patient's needs assessments and care packages. Focus groups for service users and carers were held to discuss their perspective of the impacts of the CDST in routine use. Thematic analysis of the group discussions suggests that service users and carers believe the CDST has some potential benefits for service users, carers and staff, yet to date, it has had little direct impact on service users. The study identified a number of areas where service users and carers believed the tool could be improved in order to increase its effectiveness in routine clinical practice.

Key Words: Pathways and Packages; Adult Mental Health; Focus Groups; Care Planning; Phenomenology; Thematic Analysis.

Background

The Integrated Packages Approach to Care (InPac) model (Self et al., 2007), developed in the South West Yorkshire Mental Health NHS Trust (SWYMHT), is being used in mental health NHS Trusts throughout the North of England and is supported by the Department of Health (DoH) as a rational approach to service reorganisation and planning, based on service user needs. It supports a number of requirements for the development of effective, accessible and efficient services, such as the development of care packages based on need, the identification of skills needed to provide the packages of care and interventions, and the potential to provide a basis for Payment by Results (PbR) in mental health services (DoH, 2002; Audit Commission, 2006).

At the core of InPac are the (i) revised Health of the Nation Outcome Scale (HoNOS Plus) and the (ii) Clinical Decision Support Tool (CDST), which constitute a standardised needs assessment and forms the first step of a structured decision making process for clinicians to allocate service users into the correct need group or cluster. The 13 empirically derived need groups are listed in Table 1.

Table 1: CDST's 13 Empirically Derived Need Groups

1. Acute Non-Psychotic (Low Severity)
2. Acute Non-Psychotic (Medium Severity)
3. Non-Psychotic (High Severity)
4. Non-Psychotic Disorder Of Over Valued Ideas
5. Non-Psychotic Chaotic & Challenging Disorder
6. Drug & Alcohol
7. First Episode Psychosis
8. Chronic Severe Mental Illness Group
9. Chronic Severe Mental Illness (High Symptom Group)
10. Severe Psychotic Episode
11. Severe Depression
12. Dual Diagnosis
13. Assertive Outreach

Recommended packages of care for each need group have been developed which include information about services provided and their aims and interventions. With this new model, clinicians are able to match the service user with the most appropriate need group for their needs, and then refer to the recommended care package for that need group. Each care package lists the services and interventions that *should* be included and additional ones that *may* be included for service users in that need group.

The InPAC approach provides a framework for the organisation and delivery of mental health services. It promises to provide local services with the following:

- A shared language and framework for making clinical decisions.
- A rational basis for care pathways and packages.
- A basis for clinical supervision of care coordination.
- A method to facilitate case-mix analysis and caseload management.
- Guidance on appropriate activities provided by teams.
- Aggregated data that will indicate demand for services.
- A rational basis for decisions on service priorities.

(Rigby & Self, 2002, Interim report)

The InPaC model was initially developed in the North Kirklees locality of SWYMHT and has been disseminated to 6 other mental health NHS Trusts in the Northern region of England. These Trusts are involved in the Care Pathways and Packages Project which aims to test a classification system based on the CDST's 13 statistically and clinically driven need groups. The project was considered by the DoH to be a success and support has been provided for further work to develop the model. The main findings of the pilot study were that the need groups were generalisable across the 6

participating Trusts and clinicians were able to allocate 94.2% of service users to the 13 need groups (Greene & Rigby, 2006).

Despite its increasing use in mental health services, and the support from the DoH, the CDST is a clinically driven tool and had not been considered from the service user and carer perspective; no service users and carers were included during the original development of the model or in its implementation. It was therefore felt that the tool should be evaluated from the service user and carer perspective in order to determine the benefits and potential impact on service users and their carers and assist in identifying any difficulties or issues in its use. This evaluation was part of a project examining the use of the CDST in care planning and staff utilisation and perspectives of the tool (Roberts, 2007).

Research Questions

1. What are Service Users and Carers views of the CDST method of planning care compared to the traditional format?

2. To what extent have Service Users and Carers been informed and involved with the CDST care planning process?

Methodology

Design

This was a qualitative phenomenological study which used service user and carer focus groups to elicit themes of participants' views. The focus groups were designed to elucidate the perspectives of service users and carers of the use of a Clinical Decision Support Tool in routine care planning.

Service User & Carer Involvement

Service users and carers were involved throughout this study as part of the project team which also comprised of members of the InPac development group and research staff. Their roles were to oversee the management and governance of the project and to assist with the facilitation of service user and carer focus groups and the interpretation of the data derived from the focus groups. Service user and carer members of the team also assisted with data entry and analysis.

Setting

This was a single-site study of North Kirklees within secondary care services in South West Yorkshire Mental Health NHS Trust (SWYMHT).

Sample and Participants

A no-nprobabilistic purposive sample of 12 service user and 10 carer participants were recruited for this study; 2 other carers could not attend on the day of the focus group. Participants were people using Trust services and were recruited from Trust Service User and Carer groups, day centres,

Community Mental Health Teams and through the Patient Advice and Liaision Service (PALS). The lead researcher attended several of these forums advertising the project and distributed leaflets explaining the project's aims. Leaflets were also distributed by Trust staff who then referred potential participants to the lead researcher.

The sample size was based on recommendations for achieving data saturation in nonprobabilistic qualitative studies (Guest et al., 2006). Data saturation is defined as "the point in data collection and analysis when new information produces little or no change to the codebook" (Guest et al., 2006, p. 65). This study found that when using a homogenous sample in phenomenological research[1], theoretical data saturation had largely occurred within 12 participants with 92% of the total themes identified. Within the present study, we therefore proposed to recruit 12 service users and 12 carers to provide an exhaustive and variable data set of themes related to the impacts of the CDST on their experiences of care planning.

Ethics

The service user and carer focus groups were facilitated by the lead researcher and service users and carers from the project team. All service users and carers who were part of the project team had honorary NHS contracts and full Criminal Record Bureau (CRB) checks prior to the commencement of the study. Due to the possibility that emotive topics may have been discussed within the focus groups, in order to protect the emotional and psychological well-being of the group members, they were held on CMHT premises so that members of staff were nearby in case group members became distressed. Debriefing sessions were held for the facilitators to ensure their well being.

Measures

Focus groups for service users and carers

Responses from service user and carer focus groups were transcribed and interpreted using Thematic Analysis to elicit underlying themes of expressed views (King, 1998; Crabtree & Miller, 1999). The essence of this approach is that the researcher produces a list of themes identified in their textual data. Some of these will usually be defined *a priori*, but they will be modified and added to as the researcher reads and interprets the texts. The issues discussed within the service user and carer focus groups were prompted by a list of topic areas for discussion (see Table 2) which were defined *a priori* before the commencement of the focus groups. The schedule was developed by the research team including service users and carers, some of whom had knowledge of the CDST, and was taken to independent service user and carer reference groups for consultation and approval prior to the commencement of the study.

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[1] It is important to note that one must assume a certain degree of sample homogeneity because within purposive samples participants are chosen according to a common criteria. The more similar participants in a sample are, in relation to the research objective, the sooner one can expect to reach saturation.

Table 2: Service Users & Carers Focus Groups – Topic Areas for Discussion

No	Theme
1	What do people know about the CDST?
2	What do people think about this method for assessing needs and planning care?
3	What do people think about the clusters?
4	Would people prefer to be assessed by individual clinical judgement or by a standardised tool such as the CDST?
5	What do people think the benefits would be of staff using the CDST? e.g. • equal access to services • understanding between services / teams • linked up care packages
6	Do people think there are any potential problems with the CDST? If yes, what are they?
7	What do people think about the tool's terminology / wording?
8	To what extent have they been involved in their own care plans?
9	How much detail have they been shown of the CDST / their cluster?
10	To what extent are people satisfied with their care plans?
11	What improvements would people like to see made to the CDST or care planning process?

Procedures

A research steering group was formed to oversee the project's co-ordination and progress. This group included the lead researcher, representatives from the local NHS Trust R & D department, local NHS clinical managers and service users and carers who became honorary researchers for the project. A full briefing was given to the project team on the background of the Health of the Nation Outcome Scale (HoNOS) Plus and the CDST, including training in using the tools for need group assignment and care planning using case vignettes.

Service users and carer participants in the focus groups were recruited via Trust Service User and Carer Reference groups and forums, NHS day centres (Pathways), Community Mental Health Teams and through the Patient Advice and Liaision Service (PALS). Leaflets advertising the

project were distributed by the researcher and by Trust staff who then referred potential participants expressing an interest to the researcher. Potential participants were then invited to attend focus groups to discuss their views on the potential impact of the CDST for service users and staff. A total of 22 service user and carer participants were recruited for the focus groups which were held over 3 sessions in the North Kirklees area.

The lead researcher and service user and carer researchers from the project team facilitated the groups and manually recorded the topics discussed. The lead researcher approached all focus groups from an independent perspective in order to gain unbiased views from participants and used the pre-determined topic areas (Table 2) as a semi-structured schedule for the focus groups to create consistency between the groups. The lead researcher was not known to the majority of participants but had met some previously through the recruitment process.

Results

Three separate focus groups were held in the North Kirklees area with a total of 22 service user and carer participants. Efforts were made to separate the focus groups into homogenous groups of either service users or carers. However, the demands of the caring role restricted the availability of some carers, and time constraints of service users meant that this was not possible so there was some blending of participant groups. The focus groups commenced with a brief introduction to the HoNOS Plus and the CDST care planning model so that participants were informed about the model under discussion. This briefing was not carried out prior to the focus groups as part of the investigation was to find out how much service users and carers were aware of the model through their usual care pathways.

Lack of knowledge of the model and its need groups or clusters was one of the main issues that arose out of the focus groups. The majority of service user and carer participants in the focus groups reported no previous knowledge of the InPaC project, or specifically of the CDST care planning model. This echoed the previous experiences and lack of knowledge reported by a number of the service user and carer researchers involved in the design of the study. All participants expressed their wish, and expectation, to be informed of new systems and developments that impact upon the care they receive.

The results of the discussions with focus group participants were collated and interpreted using Thematic Analysis to elicit the underlying themes from the views expressed within the groups. The main themes to come out of the discussions were as follows.

General Comments

The focus groups were very positive about the introduction and use of the CDST, after expressing some initial doubts about the tool, with most participants identifying potential benefits of the CDST model. Many reported their gratitude at the willingness of the Trust to introduce a standardised method for care planning, despite the need for some

improvements. The following comments sum up the feelings of most group members:

> "It's more uniform – not everyone's cup of tea but a good basis for the future."

> "It's a good set up, if it caters for individual needs."

> "I think this is an improvement on anything else we've had before".

> However, despite these overall comments, a number of themes emerged which expressed some concerns about the model.

1. Individuality versus Standardisation

The majority of participants commented on this theme which centred on concerns about people being "put into boxes" as a result of the need group categories, the difficulties of mental health issues being standardised, e.g. complex individual differences not being recognised, and the danger of the CDST becoming too prescriptive or mechanistic. The following comments illustrate this:

> "Mental Health does not fit with this sort of model"

> "Not all people are the same so how can need groups help?"

> "Can be construed as too mechanistic – it's important to show flexibility"

> "Need groups may override individual needs."

> Not all comments reflected these concerns however and many participants were supportive of the CDST's aims.

> "If you're going to be labelled, you may as well be labelled in a standardised manner!"

> "If you're put into the right need group, you get the right help that you need – labels are helpful!"

> "Patients will know what to expect in terms of being referred to services for that need group."

2. Subjectivity / Room for error

A second theme referred to the subjective decision making inherent within HoNOS Plus and the CDST, still leaving room for errors by staff. Participants saw this as a potential issue with the following comments illustrating their concerns.

> "Need groups could be perceived differently by different staff."

> "Service user scores can be too high or low – more objective comments are needed from their Carers."

"Accuracy of HoNOS scores and need groups depends on 1. the person doing the assessment, 2. the information they have been given, 3. information the service user / carer discloses"

"The tool is only as good as the person doing the assessment".

Again, not all people thought this issue was a problem and instead referred to it as a step forward from previous practice.

"the CDST can assist in diagnosing correctly, there's less room for subjective errors."

3.   Acceptance / Professional Judgement

This theme was identified as an issue and reflects the perceived resistance of staff to the tool and the impact it has on professional judgement or decision making; this concern was also echoed by staff through anonymised questionnaires within the main evaluation (Roberts et.al., 2007). Some of the comments that illustrate this theme are as follows;

"Staff are not keen on it."

"It's in danger of stifling the commissioning process at a local level, e.g. innovative service development."

"Is there a danger of this becoming resource-led rather than needs-led?"

4.   Incompleteness of the CDST

The CDST model was seen as being incomplete, a work-in-progress, and in need of further work or fine tuning before it is ready for wider use in routine practice across SWYMHT. Some comments were:

"Some people cannot be clustered (put into a need group) – it's important to not let them fall through the gaps."

"CDST doesn't cover all illnesses, e.g. bipolar needs to be included!"

"the need groups need tinkering".

"It's important that improvements are made promptly."

5.   Lack of Service User & Carer Involvement

This theme reflected participants' beliefs that service users and carers need to be more fully involved in the needs assessment and care planning process as they are the experts in their own, and the person they care for's, illness. The following comments describe some of their thoughts;

"Service user scores can be too high or low – more objective comments are needed from their carers."

"Service users and carers must be involved otherwise the results will be very 'one-sided'."

"The CDST is good if done with awareness of the service user on a regular basis".

6.   Language and Culture

The language used within HoNOS Plus and the CDST also emerged as a separate theme. Issues of concern included cultural issues and jargon or terminology which was not service-user friendly;

"Problems around language – culture & religion – could be improved in HoNOS (Plus) as all are using the same terminology."

"Problems around jargon etc. – simple language is needed for service users and carer's".

Not all were raising concerns however and the benefits of using standardised language were acknowledged by some members:

"All staff are now singing from the same hymn-sheet – it assists shared language and understanding."

7.   Equality

The CDST was generally felt to be beneficial in terms of equality by those participants who thought this as an important issue. It was seen to be beneficial in enabling people to be treated according to their need group, which encourages equal access to mental health services. The following comments demonstrate this;

"It's like a school anorak - everyone is treated the same and should get fair and equal access to services, e.g. if you have diabetes, the same treatment is available."

"You know what service package you are going to get."

"Clustering (need groups) means equal access to services – people will all need a 'label'."

8.   Service Commissioning

The CDST was seen to have a potential impact on the commissioning and linking up of services. Some participants identified this as an important issue, a sample of their comments are as follows:

"There's a contradiction between health & social care, e.g. in Community Care Assessments you have to be assessed as either critical or substantial to access services but it's not linked into the CDST. May impact on providing a holistic service."

"It's a method for commissioners to identify 'unmet needs' and demands on services."

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"Diagnostic overshadowing – it promotes linked up services, particularly between physical / general health and mental health."

"It should improve the quality of services."

Discussion

The strongest theme to emerge was related to 'Individuality versus Standardisation' which represented participants' beliefs about whether mental health, or individual differences in people's experience and presentation of mental health, can be subject to a standardised model. Participants were initially cautious of the idea that most service users can be allocated to one of 13 need groups, but after reviewing the research that had demonstrated that 94.2% of patients can be allocated (Greene & Rigby, 2006) most participants were reassured. However, the linked audit and evaluation of staff use and views of the CDST found that clinicians will sometimes use a 'best fit' method to do this (Roberts et al., 2007). This supports the service user and carer concerns about 'putting people into boxes' or giving them a label. Despite this, the focus group participants agreed that as long as the model was flexible enough to be responsive to individual differences, it would be a valuable tool to use in care planning and could help patients to know what to expect from their care plans.

The theme 'Subjectivity / Room for error' reflected participants' fears that there is still some potential for human error in the coding and scoring of the assessment which could lead to the wrong need group being allocated. However, the model relies upon accuracy of information from a variety of sources and also has positive and negative indicators built into the process so that people's symptoms can be matched against a profile for each need group. This appeared to allay concerns, and there was acknowledgement that the CDST model presents less opportunity for subjective errors in decision making than with traditional models of care planning.

The theme 'Acceptance / Professional Judgement' reflects concerns about the impact of the CDST model on decision making at an individual clinician, practice and strategic level. The focus groups discussed the importance of whole systems implementation in taking forward changes in practice, as necessary for their success, and the impact on local service commissioning. This theme reflects how participants felt the CDST might take away individual professional judgement from the decision making process in care planning and could therefore be resisted by some staff. There was some concern that standardising the process would lead to the loss of clinical judgement in complex situations where flexibility and responsiveness is required.

Many participants raised their concerns about the clusters not adequately covering all major diagnoses and this was something that they not only want to see improved, but expressed a wish to be involved in the revision work. This was reflected in the theme 'Incompleteness of the CDST' and the potential implications of this for the reliability and validity of the model if left in its current format. Although the need groups have been demonstrated to cover 94.2% of the clinical population in adult mental health, participants expressed concern that the model does not adequately describe bipolar disorder, a common diagnosis, and eating disorders. It

should be noted however that these conditions *can* be at least partially addressed by existing need groups, albeit non-specific ones, e.g. elements of bipolar can be covered by the 'Severe Depression' need group and elements of eating disorders can be covered by the 'Non-Psychotic disorder of Over Valued Ideas' need group. These allocations are not precise, however, and greater concordance between the need groups and these disorders would be useful.

Within the 'Lack of Service User & Carer Involvement' theme, the participants were fervent in their belief that they should be included in the care planning process and would also welcome the opportunity to contribute in identifying their support needs. All participants in the focus groups were asked if they had been involved with their, or the person they care for's, care plan. A small number of people had taken part in their care plans, usually with their Community Psychiatric Nurse, but no participant had been involved with the CDST care planning process or knew if they had been allocated to a need group. This may be a staff training issue as the CDST does not specifically exclude service users or carers from being involved in the process and indeed, would greatly benefit from their inclusion.

The theme 'Language and Culture' was related to participants' perceptions that the language used within the CDST reflects the development of the model by clinicians only. They felt that, in parts, it was apparent that no service users or carers had been involved in its development as it uses "lots of jargon" that may not be easily understood by lay people. Some participants also referred to the use of stigmatising language, e.g. the use of 'chronic' in some need group descriptions which does not give consideration to the concept of the recovery model (Repper & Perkins, 2003). Additionally, the language and concepts within the CDST were not seen to embrace cultural perspectives which could potentially marginalise black and minority ethnic patient groups. However, there was recognition by some group members that by standardising the language used within needs assessment and care planning, staff across teams and areas could understand each other more easily when discussing new referrals to services.

The theme of 'Equality' was, for service users and carers, one of the most positive indicators of the potential benefits in using the CDST model. Most participants thought that by standardising care packages, based on the needs of need groups, patients could expect to see a real improvement in having more equal access to services. Service user's perception was that they have been signposted to services based on their address, the knowledge and skills of their key-worker, and the existing choice of pathways of their referrer. For this potential impact alone, many participants reported that they would welcome the routine use of the CDST in care planning.

The theme of 'Service Commissioning' is in some ways linked to the theme of 'Acceptance / Professional Judgement', in that it relates to the CDST's impact on decision making in service reconfiguration and commissioning, but in a much more positive way. Participants felt that there would be potential benefits in using the CDST to indicate local demands on services and areas of unmet need which could then inform the commissioning

process. There was also some discussion about how the CDST could link in to the access requirements of other stakeholders such as Social Care, providing a more holistic service to NHS patients. The ability of service users and carers to foresee the potential impact on services at all levels indicates a good understanding of NHS systems and processes and should encourage a greater propensity to collaborate with service users and carers in developing new interventions or services.

Conclusion and Recommendations

The themes expressed in the service user and carer focus groups were wide and varied and had a balance of positive and negative views, with most participants reporting that they felt more confident about the model having talked through their concerns in the groups. The CDST appears to have many potential benefits, from the service user and carer perspective, in attempting to standardise care planning which, due to the influence of many factors, was regarded as a complex, idiosyncratic process. The consultation of service users and carers through focus groups has shown that they are mostly positive about such developments and are able to understand the implications of routinely using the CDST model.

The main benefits identified through this study are:

- Service users knowing what support they can expect through their care plans.

- Less opportunity for clinician's to miss important elements of a recommended care plan.

- Greater understanding between staff from different services and teams through a shared language.

- An improvement in access to services for all patients and reduction in equalities.

- More informed decision making in the reconfiguration and commissioning of local services.

However there are some issues which service users and carers felt needed to be resolved and there are recommendations for improving the model.

The main concerns were focused on:

- The need for accurate information when doing the assessment.

- The potential for individual clinical judgement to be lost in care planning.

- The need groups, some of which need refining to more adequately meet the needs of diagnoses that are currently missed.
- The lack of service user and carer involvement in developing care plans with the CDST.

- The stigmatising language and jargon that the model uses.

The issue of no service user and carer involvement in the original development of the model is not an easy one to resolve. A multi-disciplinary working group of managers and clinical staff in North Kirklees was formed in 2000 and developed the CDST model over a 2 year period; at that time no public involvement was invited, which in retrospect, failed to incorporate the views of service users and carers. However, this study has demonstrated that service users and carers want to be part of the improvement process as they generally support the CDST model and feel they have a lot to offer to the development of the framework.

Acknowledgements

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