Hull CCG-funded Studies:
Impact Report
April 2017

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1. Introduction

This report provides information to the Planning and Commissioning Committee on the impact of Hull CCG-funded studies for information and discussion. It demonstrates that Hull CCG is continually striving to be at the forefront in making the promotion of research and the use of research evidence a part of its core work.

2. Background

The UK government has stated its firm commitment to promote research throughout the NHS which it sees as essential to continually improve effectiveness of health services and patient outcomes. Indeed, there is an expectation that the UK will be the first research-led health service in the world.

A number of current policy documents have placed a strong emphasis on research activity in the NHS:

- The NHS Constitution 2015 (DoH, 2015)
  One of these principles includes a commitment to 'the promotion and conduct of research to improve the current and future health and care of the population'.

- The NHS White Paper, Equity and Excellence: Liberating the NHS
  'The government is committed to the promotion and conduct of research as a core NHS role. Research is vital in providing the new knowledge needed to improve health outcomes and reduce inequalities'. (DoH, 2010, p.24)

- The government response to the NHS Future Forum report made the following commitments with respect to CCGs and research:
  '*CCG's legal duties should reflect their key role in making sure that, at a local level, the need for good research, innovation and a strong evidence for clinical decisions is paramount*'. (DoH, 2011, p.26)

This mandate is recognised within the latest NHS Planning Guidance 2016/17 – 2020/21 which raises the issue of how commissioners can support research, innovation and growth by building on the research infrastructure which can be a pathway to generate new innovative approaches to service development that impact on service delivery and improve patient outcomes.

In recognition of this national agenda, an NHS Hull R&D Steering Group was established in 2013. One of its remits is to develop transparent processes for promoting, identifying and supporting locally driven projects that will help and inform CCG strategy and future research.

Since 2010, Hull CCG (then PCT) aimed to promote and support locally driven projects. From 2013, through an agreed pathway and procedure, the process was centrally coordinated by the North Yorkshire and Humber R&D service. Since 2016, the results of these studies have begun to be fed back to the CCG from researchers who have reached the end of their

studies. Commissioning Managers at Hull CCG have sought to translate this research evidence into practice in order to better-inform commissioning decisions and make a positive impact on the local Hull population.

3. Study summaries

The studies shown below are studies that completed in 2016/17 that were funded by Hull CCG. The 'impact' section of the table indicates if and how Hull CCG seeks to translate the results of the studies into change at a local level. The associated appendices provide the full end of study reports or executive summaries with recommendations for commissioners.

3.1 Budget Year 2010 – Study summary

Christopher Dalgliesh: The Impact of Socioeconomic Factors on Place of Care and Place of Death	
Purpose	The principal purpose of this study is to investigate whether Socioeconomic Status (SES) is associated with place of death in Kingston- upon-Hull, and if so, to understand some of the contributory factors that may be involved, from the viewpoints of health and social care professionals. Specific objectives are to: • Explore whether there is an association between SES and place of death in Kingston- upon-Hull. • Identify understanding of the effect of SES upon end of life care needs, including any relationship to place of care and place of death, among a range of health and social care practitioners. • Explore the challenges of providing end of life care in the context of lower SES, from the perspective of a range of health and social care professionals. • Generate and explore recommendations for health and social care professionals to improve the experience of end of life care among people of lower SES.
Funding	Funded £60,000.00 by NHS Hull as one-off payment to the University of Hull in 2010
Planned activities	The funding for this ended in March 2016. Data analysis is taking place and the work is being written up and submitted as a thesis. The submission of this is expected Spring 2017. The work was presented at the CCG R&D event in April and a report will be prepared for the CCG as a final report (although the larger thesis will also be publically available in due course).
Status	The study is completed. The executive summary and recommendations from the end of study report can be found in **Appendix 1**.
Impact	The outcomes of the study will be shared with colleagues in public health and a Macmillan GP. Once their views are obtained, the CCG will decide how to take this forward.

3.2 Budget Year 2013-14 – Study summary

Tracy Flanagan: A Pilot Feasibility study to examine the use of carers views to inform risk Assessments in Mental Health	
Purpose	The study evaluated the effects of increasing carer involvement in dialogue around risk assessments.
Funding	£42,000
Activities to date	Findings attained, end of study report produced
Planned activities	Conclusions attained
Status	The findings have been used to support the implementation of improved carer strategies within Humber NHS Foundation trust inpatient services. Carer and family reception meeting have been standardised and training for Family Inclusive Care Coordination is being delivered to staff. The end of study report can be found in **Appendix 2.**
Impact	Hull CCG feels that the study's results will add support to the involvement of carers and families in the delivery and planning of services. The study will inform future work around risk assessments in mental health.

3.3 Budget Year 2015-16 – Study summaries

Catriona Jones: Lesbian, Gay, Bisexual and Transgender (LGBT) Experiences of Primary Care in Hull	
Purpose	LGBT individuals face unique health disparities, which are largely unexplored in the population of Hull. It was anticipated that any exploration of the experiences of being LGBT and accessing primary health care in Hull would provide a greater understanding of their experiences in healthcare, identify their specific needs, and facilitate the development of a number of recommendations to address the health disparities and unique health needs of LGBT population in Hull. Our research was designed to explore experiences of LGBT groups in the context of the NHS commitment to equality and fairness, with a view to identifying good practice, and also to highlight areas where improvements could be made. The overall aim of this study was to understand the experiences of those who identify as LGBT when they engage with primary health care services in Hull.
Funding	£30,628.00
Status	Study completed. The executive summary and recommendations from the end of study report can be found in **Appendix 3.**
Impact	The end of study report will be considered by the CCG's Equality Reference Group who will then determine if any further action is required.

Jo Bell: Access to mental health services: exploring the barriers and facilitators to helping Hull's distressed young people	
Purpose	This project aims to explore what support is available and how the various stakeholders interact in providing that support. Crucially it also aims to determine what help young people want, what they feel they have available to them and their perceptions of accessing that help. Using an online survey, interviews, and focus groups, this unique 12 month project will focus on the local community and its relationship with services.
Funding	£33856.80
Activities to date	We have successfully: secured institutional and organisational ethical approval for the research project ; appointed a Research Assistant; designed, developed and implemented an online survey for young people; designed, developed and implemented an online survey for parents of young people; established a steering group of young people and held two meetings with this group so far; undertaken in-depth interviews with young people who have experience of accessing mental health services in the local area and parents of young people who have experience of accessing mental health services in the area; undertaken 3 focus groups with professionals who work with young people with mental health difficulties; held regular meetings with the research team to ensure progress. We have started a twitter feed to promote the research and highlight issues around young people's mental health generally in the area.
Planned activities	We are currently on course to achieve our aims by the end of the project in December 2016.
Status	Study completed. The conclusions and recommendations from the end of study report can be found in **Appendix 4.**
Impact	Hull CCG responded to the study's recommendations as follows: 1. Hull CCG feels that a 'Young People's Mental Health Forum' for professionals is a good idea and something that has been highlighted as a need when discussing young people's mental health. Hull CCG will consider how best to approach this. 2. Hull CCG commissioned an online directory of locally accessible services in 2016, with the website being developed and launched jointly with young people in Hull – the website is www.howareyoufeeling.org.uk the website went live in October 2016, and is currently being reviewed and updated 3. The CCG is encouraging all schools in the area to devote some of their web space to young people's mental health with the help of HeadStart colleagues in the local authority. This will allow the 'how are you feeling ?'website to be on the homepage and accessed within schools. 4. A lot of work has been done on access to services over the last year, with a big improvement on waiting times to access services – however there is further work to be done to reduce waits further. We have also introduced a single point of access and removed the label 'CAMHS' replacing it with 'Emotional Vulnerability Hub' – this means that young people can access an emotional and mental health service which will respond to their overall need, rather than just a specialist mental health need. The Hub will work collaboratively with other statutory

	organisations and voluntary sector organisations to deliver a responsive, coordinated response that is based on individual need, and not on thresholds. The hub is currently being operationalised and will be communicated widely in due course. Young people are also renaming the service. 5. Hull CCG and the Local Authority have jointly developed a workforce development plan which is currently being reviewed and refreshed for 17/18 – we will certainly ensure that training and education is available. Hull CCG has commissioned self-harm training which is being rolled our across the workforce from the end of March 2017. Through the HeadStart programme, a lot of education on mental health is being delivered within school settings. Further investigation into how best to support GP's will be undertaken. Much of the research findings will impact on the content within the 'How Are You Feeling?' website and this will be reviewed/amended accordingly. In terms of knowledge around MH and incorporating this into school timetables, the HeadStart team are working closely with schools to review their PSHE polices and this information will be shared. It is noted that young people would prefer to be assessed face to face rather than over the phone, and further exploration around this will need to be done. Also, more information around the language used which young people have picked up on.

3.4 Budget year 2015-16: Research Capability Funding Allocation

Hull CCG was allocated Research Capability Funding (RCF) for 2015-16 of £20,000.00. The Department of Health (DoH) has defined criteria of how the monies can be spent. Based on the national guidance, a local bidding process was developed and, to aid the decision making process, a support tool developed in partnership with R&D peers from West Yorkshire. The bidding process closed in January 2016 and a decision was made before the end of the 2015-16 financial year. Summaries of the studies that are now complete are shown below.

Catriona Jones: Non-attendance and attendance in perinatal mental health care	
Purpose	To inform a larger study aimed at exploring the experiences of women with perinatal mental health problems.
Funding	£5682.00
Activities to date	During this 18-month period, a total of 76 women (58 from Hull) did not attend the first appointment with the specialist team; all of these women are included in the analysis. Referral forms were also examined for 63 women who did attend (35 from Hull). Data were transferred from Microsoft Excel to SPSS (version 24); where relevant, variables were coded to facilitate analysis. Descriptive analyses were carried out and data presented in graphs and tables as appropriate. Significant differences between attenders and non-attenders were analysed using Chi-Square Tests and Fisher's Exact Tests where necessary for categorical variables and independent t-tests for continuous variables.

Planned activities	We will discuss these findings with members of the specialist perinatal mental health team with the aim of interpreting results and drawing up a plan for further actions and research.
Status	Study completed. The conclusions from the end of study report can be found in **Appendix 5.**
Impact	Dialogue via the R&D team has taken place with the study lead and the designated commissioning manager from Hull CCG. The findings have been taken to the Perinatal Mental Health Team in Hull and, as a result, potential changes to practice are being explored. To further the local impact of the study beyond the Maternity Services forum other options are being explored of presenting to wider forum(s) with the designated commissioning manager at the CCG. So the local impact of the work is still underway.

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Appendix 1

Research Project Final Report

A. Project title

The impact of socioeconomic status on place of care and place of death.

B. Abstract/Executive summary

Background

People from poorer social classes experience worse care outcomes at the end of life, and are more likely to die in hospital. Although a limited amount of research has been conducted into the perspectives of the healthcare and medical professionals involved in care at the end of life, little has addressed attitudes to social class.

Methods

Eight focus groups with 48 health and medical professionals were conducted in Kingston-upon-Hull, UK. Participants were asked to discuss their impressions of socioeconomic status in relation to delivering care at the end of life, especially with regard to decision making related to places of care and death. Data were analysed using a systematic qualitative method based on the principles of grounded theory.

Results

Three themes emerged:

Communication: The ways in which professionals perceived communication was considered differently (positively and negatively) between different social classes.

Socio-demographic factors: Medical practitioners were more likely than other participants to accept social class as influencing their decision-making. Patients from higher socioeconomic backgrounds were identified as better equipped to express their wishes. However, closer family networks associated with poorer families were seen to offer more support. Practitioners also expressed a greater sense of paternalism towards poorer patients.

Organisation of care and resources: Inequity emerged in narratives regarding inability of patients' relatives to cope at home or with admission to hospital at the end. Practitioners recognised that needs varied according to socioeconomic status and practised tailored care to provide equity. There was a reluctance to discuss this, however.

Conclusions

Practitioners found difficulty in discussing differences of social class, but still tailored their care to patient need. This duality presents challenges for palliative service management.

Recommendations

- A limited understanding of equality (where everybody is treated the same way) and equity (where everybody is given individualised support to achieve at least a minimum level) was evident. Tailoring of care in this way was still conducted, but informally by individual practitioners. This informal nature (and associated issues of limited record keeping) risks inconsistencies across the service, duplication of effort and patients *falling through the cracks.* **Ensuring practitioners are aware of these issues is recommended.**

- An assumption that *richer patients have it better* was common. While it appears to be the case that material wealth is useful in resilience to unplanned change, patients from higher socioeconomic groups were often seen as more socially isolated. Service availability in different communities may also offer challenges. **Practitioner awareness of these challenges may be beneficial.**

- The importance of effective communication between all involved in the end-of-life process was seen as key to achieving preferred outcomes for the dying person, and securing their emotional legacy for family members. Maintaining effective interpersonal and inter-professional communication and relationships was seen as key for maintaining the patient's legacy, and for supporting family members' future interactions with healthcare (and particularly end-of-life) services.

Appendix 2

Research Project Final Report

A. Project title

A pilot feasibility study to examine the use of carer views to inform risk assessments in mental health.

B. Abstract/Executive summary

Background: Involving carers is a key priority in mental health services. Carers feel sharing information regarding 'risks' posed by service users is currently problematic and seldom takes place.

Aims: This study evaluated the effects of increasing carer involvement in dialogue around risk assessment.

Method: Staff-carer risk consensus scores were measured pre/post introduction of a structured dialogue. Carer experience with involvement was surveyed pre-test and compared with the post-test intervention group.

Results: Statistically significant differences were found in carer experience across 4 out of 6 areas of risk. No statistically significant differences were found in relation to staff-carer consensus scores.

Conclusions: Findings provide support for increasing carer contribution to discussions regarding risk. Further work investigating the use of structured approaches to embed carer involvement in clinical practice is warranted.

C. Background to the project

Locally with the Humber Foundation NHS Trust (HFT) a number of SUIs (Serious Untoward Incidents) investigations were undertaken following the deaths of service users within acute inpatient mental health units. Families and carers reported not being involved in discussions with staff around the risk posed by the service user and a failure of services to effectively listen to their concerns about risk. In 2011 a literature review was undertaken to explore the following question "what interventions or approaches have been used to involve carers of people with mental health difficulties in risk assessment and management?" The review indicated that whilst there was a substantive body of policy documentation and guidance advocating the importance of involving family members and carers in services (both generally and specifically in relation to risk assessment) (NICE 2005, DH 2010, Clancy et al 2014) levels of family and carer involvement were variable both nationally and locally (Crombie et al 2007). Ignoring the views of families and carers, or not informing them of significant events, impacts on their ability to care effectively post discharge compromising both their safety and that of the service user they support (Gray et al 2008). When dialogue does take place, it can be difficult as professionals' perception of what constitutes risk (Littlechild & Hawley 2010), how they prioritise risk (Ryan 2002) and even the language they choose (Clancy et al 2014) does not reflect that used by carers and/or service users. However, Crombie et al (2007) argue the main barrier to carer involvement is the conflict between service users' right to privacy and confidentiality and carers' need for information. This dilemma sees professionals unclear about what they can and cannot share and is sometimes used a way of avoiding involvement and communication with carers' (Gray et al 2008). The capacity for meaningful discussion is therefore limited leaving families and carers unable to communicate vital information which could provide a more comprehensive representation of the service-users illness. Failure to include carer views has negative consequences and outcomes for services, service users and their families. Involvement positively affects service outcomes potentially reducing inpatient stays and subsequent costs (Bee et al 2015).

To support better understand of how to successfully involve carers, semi-structured interviews were undertaken in 2011 with carers (n=17) to explore their experiences of being involved in risk

assessments and canvas their views on what level of involvement they would like to see. Key themes emerged following analysis relating to risk assessment and management;

1.   Carers' understanding and knowledge
2.   Engaging with services in discussions of risk
3.   Experience of risk assessment and management
4.   Experiences of isolation and burden
5.   What carers wanted to engage in discussion

In September 2013, a review of service user case notes was conducted within the in-patient services to look at staff contact with carers and determine the focus of this contact and whether discussion regarding risk took place. The psychiatric notes of the first 5 clients discharged from each of 6 inpatient units within HFT from 1.10.13 were reviewed (n=29). Using a data capture form, descriptive quantitative data was collected and the content of contacts analysed using content analysis.
The results showed that in cases in which the initiator was known, and recorded within the notes, the staff initiated 45.1% of the overall contact with carers, with direct discussions around risk only accounting for 1.11%.The study highlighted the need for nursing staff to be further supported to engage carers more routinely in practice in line with policy.

D. Objectives

The aim was to investigate the impact of increasing the involvement of and level of contribution that carers make in the assessment of risk, and specifically;

(1) What impact does involving carers in risk assessment have on their levels of satisfaction around their involvement with risk assessment and services?

(2) What impact does involving carers in risk assessment have on the consensus between carers and practitioners about the areas and levels of risk a service user presents with?

E. Method

A training and intervention protocol was developed for the Carer Involvement in Risk Assessment (CVIRA) pilot study informed by the literature review, carer interviews, staff-carer contact review, carer feedback and consultation events.

The study was a pre-test / post-test design. Pre-test data from 60 carers (pragmatic control group) was gathered between November 2014 and April 2015. A survey of carers' satisfaction with involvement in the risk assessment process plus their overall satisfaction with the admission was undertaken by telephone with carers (not involved in the intervention arm of the study) of adults (18-65 year olds) admitted to one of four inpatient units.

Following this, the intervention was introduced which was a structured dialogue undertaken face to face between nurse and carer around the risk assessment tool used in the Trust (GRIST). MHNs from four units attended a training session delivered by the research team. This consisted of a presentation evidencing importance of involving carers' in the risk assessment process, information about the structured dialogue and the research information/consent process. Nurses undertook a role play at which they were required to achieve an 80% pass to demonstrate understanding. Fidelity was re-checked during the first intervention and remained at above 80% for all nurses. A total of 43 nurses were trained.

Between June 2015 and April 2016 a total of 36 interventions took place in which carers were asked to score 6 areas of risk using a visual rating scale. Consensus between the views of carers and staff

was also measured. Two to three weeks later the carer was contacted by telephone and asked to undertake the carer satisfaction survey.

F. Results

Most carers in the intervention group were satisfied with every aspect of the service that was evaluated. Generally a greater percentage of carers in the intervention group than in the control group were satisfied with each aspect of the service that was evaluated. The difference between groups was statistically significant for the questions: "Did you get the opportunity to say what you were worried about?"(85.3, <0.001), "How satisfied were you that they focussed on the right area of risk?" (85.2%, <0.001), "How satisfied were you that the care team understood the severity of the risk?" (84.8%, <0.001), and "Overall how satisfied were you with the service?" (88.2%, <0.001) (see Appendix One).

Data were available on 32 carer-staff pairs to calculate the GRIST discrepancy scores. The mean pre-discussion discrepancy score was 10.7 (SD=9.81). The mean post-discussion discrepancy score was 9.56 (SD=7.69). The mean change in discrepancy score was 1.16 (SD=1.29) although this change was not statistically significant (t=0.891, df=31, p=0.391, 95% CI (-1.19,3.88)). No significant centre differences were found from the one-way ANOVA (F(3,28)=1.00, p=0.407), although it should be noted that three of the four centres contributed very few carer-staff pairs (n=3, n=19, n=4 and n=6 for the four centres).

A paired t-test was used to see whether the carer-staff GRIST discrepancy reduced after the intervention. The mean discrepancy was less after the intervention however the change wasn't statistically significant. The change in discrepancy between the four centres was examined by one-way ANOVA and no significant differences were found. The overall effect size for the before to after convergence in GRIST scores between staff and carers was 0.158 (see Appendix Two).

E. Discussion

Current literature states carers continue to feel uninvolved and under-utilised (Cree et al., 2015). How this gap might be closed is unclear as nurses lack the skills, training and confidence necessary to work effectively with carers (Stanbridge et al., 2013).

The study results indicated carers who participated in the structured dialogue expressed, when compared to the control group, increased levels of satisfaction.

85.3% of carers in the intervention group were satisfied that they had been given the chance to discuss their concerns, an increase of 26.9% over the control group. However their scores may have reflected overall experience, suggesting carers view any contact positively (Whelton et al., 1997). For the 15% who were dissatisfied, they may have not felt listened too, may have been dissatisfied with the intervention or the staff conducting it, felt misunderstood or even took issue with the language or terminology used. This would support Clancy et al. (2014) in that the 'risk language' used by professionals is different to that of service-users and carers.

The questions, "How satisfied were you that they (staff undertaking the intervention) focussed on the right area of risk?" and "How satisfied were you

that the care team understood the severity of the risk?" related to carer satisfaction nursing staff were listening to them. The importance carers place upon being heard (Worthington et al., 2013) and want to contribute to care (Cree et al., 2015) cannot be overstated. These results reinforce this, as 85% of carers in the intervention group expressed greater satisfaction in this area, with figures relating to professionals acknowledging the severity of the risk more than doubling when compared to the control group.

The increase in satisfaction regarding teams sharing information and carers feeling involved in the decision making process was insignificant. This is consistent with other literature in that carers perceive professionals do not reciprocate in information sharing (Rapaport et al., 2006), sometimes withholding details about significant events or issues of safety (Gray et al., 2008). Carers may not have been convinced they were equal partners and decisions were still being made independently by staff, a point also raised by Cree et al. (2015) in relation to carers' involvement in care planning. The DOH (2014) consensus statement on information sharing and suicide prevention states that, 'Obtaining information from and listening to the concerns of families are key factors in determining risk', (p7).

No significant differences were found between carer and staff consensus figures regarding perceptions of risks posed by services users across all six areas of the GRIST. This could be because insufficient interventions were completed to detect differences as the original power calculation stated recruitment should total at least 52 participants. However, lack of consensus may infer underlying disagreement and reflect literature suggesting carers and professionals hold differing perceptions of what constitutes a risk and how serious that risk may be (Ryan, 1998; Littlechild and Hawley, 2010). These findings indicated carers tended to rate risks higher than staff.

Some convergence was evident with the trend for carer-staff consensus scores to be closer together, particularly in relation to self-harm, overall changes were not statistically significant. However neither group substantively altered their ratings across any of the risk domains. Within person changes were also minimal and the majority of carers or staff did not change their rating pre to post intervention for a majority of the domains. As only 8 out of 32 risk assessments were updated within 72 hours of the intervention, it implied staff were either not re-evaluating their scores after listening to the carer or not updating the GRIST. Gilbert et al. (2011) evaluated the use of the GRIST risk assessment and found an unexpectedly low number of risk assessment reviews were undertaken by staff. This lack of post staff risk scores and individual changes, meant that despite engaging in a structured dialogue focussed upon their perception of risk, neither group significantly changed their ratings and continued to hold conflicting views about risk concerns.

Comparison between participating units showed marked differences between the numbers of interventions undertaken. Site 2 recruited most carers and had a higher staff to patient ratio, fewer beds and a larger percentage of permanent staff. At the other sites, operational differences including heavy workload, challenges of acuity and a rapid turnover of patients limited the time nurses had to engage with carers. Pressures upon nursing staff working acute environments are well documented (Stanbridge, 2012), and these findings suggest should nurses be adequately resourced to increase carer involvement.

Overall these results are promising and demonstrated significant differences between the pre and post intervention carer groups, but should be treated with caution as groups were independent of each other and the study did not use a validated data collection tool. Nurses may have introduced bias to the intervention sample through controlling access to which carers could be approached for recruitment. As suggested Gray et al., 2008), they tended to recruit carers whom they had existing

positive working relationships often citing a patient's right for confidentiality as a barrier to carer engagement. Also, as health interventions are subject to a number of confounding variables, it is difficult to attribute change with any confidence to one single intervention (Craig et al., 2008).

Recommendations

- The ways in which staff are supported to initiate and maintain contact with more challenging and difficult to reach carers warrants further enquiry
- Professionals need to be clear about what they can and cannot share
- Further study should be undertaken to identify a 'common language', acceptable to providers, service users and their carers to improve carer involvement and facilitate meaningful discussions about safety concerns.
- Organisations serious about involving carers should ensure there is adequate staffing to facilitate collaborative planning and management of service user safety.

Appendix 3

Lesbian, Gay, Bisexual and Transgender (LGBT) Experiences of Primary Care in Hull

EXECUTIVE SUMMARY

- This survey included an online questionnaire answered by 78 people, aged from 18-74 (with 12% being over 55) from across the LGBT spectrum in Hull and 3 qualitative focus groups with a total of 13 people from the local LGBT community. They were asked a broad range of questions about their experiences of Primary Care in the City.

- Survey respondents indicated a wide and frequent use of Primary Care services, ranging from GPs, Practice Nurses and Pharmacists to Community Nurses and Community Mental Health Professionals. Most respondents reported accessing services between 2-5 times a year with 26% indicating between 6 and 10 instances per year.

- Overall there were high levels of satisfaction with the care that LGBT people received from Primary Care services and professionals in Hull. The majority of survey respondents felt they always received 'excellent care' from Primary Care professionals and a clear majority felt comfortable in disclosing their LGBT status to a Primary Care professional.

- Of the 39 respondents who had accessed sexual health services in Hull almost 80% felt their sexual health needs had been fully met and the majority of respondents would recommend the service to their friends.

- The majority of the relatively small negative responses within both the survey and focus groups focussed on two issues – 1) Lesbians sometimes felt that they were treated as heterosexual – offered pregnancy test for instance – even after disclosing their sexuality and 2) amongst the small number not comfortable with disclosing their sexuality there was a belief that this could cause a negative reaction.

- Another less positive finding from the survey and focus groups was that transgendered respondents reported that Primary Care professionals often have poor levels of knowledge about transgender issues and the process of gender change.

RECOMMENDATIONS

- Adopting strategies to promote a non-heteronormative healthcare environment for patients may provide LCBT service users with some confidence that disclosure will not be met with judgement. For example, simple steps such as signalling that the organisation is LGBT friendly, providing gay friendly literature/magazines, displaying posters featuring same sex couples, and providing brochures for LGBT support groups may reassure some LGBT patients.

- Having knowledge of the sexual orientation/identity of a service user pre consultation may be a valuable component of the encounter, as it can guide the interactions during the consultation. If a patient has previously self-identified, data suggests it is frustrating to have this disclosure ignored.

- Every healthcare encounter is an opportunity to have a positive effect on the health of a service user. Health professionals, practitioners and all other staff working in primary care

should maximise this potential by learning more about LGBT identities and needs and move towards greater LGBT cultural competency.

Appendix 4

Access to mental health services: Exploring the barriers and facilitators to helping distressed young people in Hull and the East Riding

Taken together our findings suggest a number of important factors for services to embody in improving access to mental health services for young people in Hull and East Riding. Firstly, lack of knowledge and understanding of mental health (including language) can be intimidating for young people. Young people often struggle with the shame and stigma associated with mental health and with emotional literacy. It can leave them scared.

Furthermore, when they speak to adults and make sense of this, there can be mixed results, most notably when adults in schools lack awareness of mental health issues and how to deal with them. This can be a barrier to accessing services. Young people need to feel that there are people they can trust, and be empowered to take steps to access services. This requires the adults in their world to more fully recognise them as service users.

A major reason for many parents/carers not seeking help for their child was that their child did not wish to seek help. So there needs to be: realistic information about the nature of mental health and the nature and purpose of local services that minimises the continuing stigma of having a mental health problem; recognition that it can be the parent who serves as the person coordinating care to the best of their ability so parents/carers need to become informed about their children's specific issues; recognition that young people who lack support from parents/carers, family and peers are a particularly vulnerable group. It is imperative that this group have equal access to services.

To make help seeking easier there needs to be: up to date and widely available information about the options for help that can be used by everyone; recognition that most mental health issues need not go to CAMHS. Our findings indicate that online resources may be a valuable source of information if perceived to be trustworthy and point to the need for: a "one stop" webpage that gives contact details for all local mental health and relevant services and practical ways young people and parents/carers can seek help directly. This information should be in a format that gives young people, parents/carers, school staff and primary care staff more confidence that they can help the young person to find help, despite not having a full understanding of mental health issues. Our findings caution against the use of online resources and applications that offer emotional and mental health support for and young people as a substitute for face-to-face support.

Our findings suggest an important role for schools in Hull and East Riding in supporting young people's mental health. Firstly, there is an urgent need to raise awareness of young people's mental health and developmental disorders amongst staff in schools in Hull and East Riding. Teachers are well placed to identify those who might be vulnerable and in need of support from specialist services. However, there is a limit to what teachers should be expected to provide. Our findings suggest schools working in collaboration with other services, professionals and parents/carers offer best approaches.

For example, young people want education on mental health in schools but our findings suggest best practice would be for this to be delivered by specialist providers (not teachers). Similarly, there is a

need for: a dedicated pastoral role in schools (this should be separate from education role, not undertaken by teachers); immediate access to independent counselling services for young people; access to peer support for young people.
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This research suggests that negotiating appropriate access to support for young people with mental health issues is complex, sensitive, and often a lengthy process. It takes a lot of courage for young people to engage in the first contact with mental health services. Young people tended to need support from an adult or peer even to begin to seek help, and needed someone that they could trust to serve that role. Trust in this sense was synonymous with confidentiality. It also appeared to involve being able to strike a balance between recognising the severity of the young person's distress, and neither minimising nor catastrophising the underlying problems.

The gap between assessment and treatment is an issue in urgent need of attention: quick access to intervention is essential. Best practice according to our respondents would be: initial assessment that is face to face where possible, making sure the first point of contact is friendly, understanding, supportive and confidential; care that is joined up and planned with one professional taking the lead, even when multiple services need be involved; care that fosters open dialogue and trusting working relationships between all parties involved (young people, their parents and carers, and the professionals who work with them). The importance of good relationships in promoting best practice is emphasised across and between all data sets in our study. Relationships are key to improving mental health: good relationships foster trust, confidence, and self-efficacy. Services need to be relationship focused: not just between practitioner and service user, but also between service providers more broadly, to enable ongoing trust and confidence from the population.

Recommendations

1. A Young People's Mental Health Forum needs to be set up for professionals who work with young people to: share practice experiences, knowledge of local services and the most up to date evidence based methods; improve the right skill-mix and promote collaborative working. The professionals' focus groups in our study were a good example of this in action. This forum would require resourcing by the CCG but could be hosted by HEY Mind on Beverley Road, Hull. Quarterly meetings might run at a total cost of around £1500.00 per annum.

2. An online directory of locally accessible services should be established and maintained by the CCG. This would not be expensive but a dedicated member of staff needs to be responsible for updating and maintaining it. It should be a well disseminated, central portal of young people's local mental health services information, including NHS, voluntary and third sector organisations. It will be important that the aforementioned YPMH forum and the directory maintenance team develop a close working relationship so that the directory stays up to date.

3. The CCG should encourage all schools in the area to devote some of their web space to young people's mental health, and this should include a link to the online directory.

4. Young people have difficulty accessing services and require help from trusted adults or peers. Access to services needs to be reviewed, with an emphasis on access being quick, easy and open. Where possible this should reduce red tape and repeated tick box assessments. We recommend that the CCG carry out periodic audits of their mental health services to ascertain whether the thresholds to obtain services are low enough.

5. Awareness raising and training / education for school staff and GPs is required as there is limited understanding of mental health problems and how to approach them in the local context. These groups are often the first to be in contact with young people experiencing difficulties so it is vital they have the knowledge and confidence in their helping responses. We therefore recommend further research to identify gaps in knowledge, understanding and skill-sets amongst these groups followed by targeted intervention.

Appendix 5

Non-attendance and attendance in perinatal mental health care

Conclusions

It is apparent from this analysis that there are some significant differences between attenders and non-attenders, as well as between women from Hull and women from the East Riding.

To summarise, women are significantly more likely not to attend the first appointment if:

- they are from Hull (especially some areas, e.g. HU9),
- they are younger,
- their relationship status is not known or they are not married,
- they are not employed (or their employment status is not known),
- they are affected by 'low mood', current or previous depression,
- they have a history of self-harm and/or suicide attempts,
- they have responded positively to the Whooley questions (in so far as they have been recorded).
- In addition, women are significantly more likely to attend if:
- they are currently suffering from psychosis or psychotic symptoms
- they have experienced a traumatic birth,
- they have bonding and attachment difficulties,
- they have a personality disorder,
- they are currently receive counselling.

Almost half of all women who missed the first appointment were seen eventually by a member of the specialist team. There were some significant differences between women who were and were not seen eventually.

Women are more likely not to be seen eventually if:

- they self-referred,
- they have been offered a home visit (women in Hull only),
- they are younger,
- they had current or previous depression.
- Women were more likely to be seen eventually if:
- they had current psychosis or psychotic symptoms,
- they had bonding or attachment issues.

The reasons for non-attendance are likely to be complex and multifaceted. While some women may feel that they do not need to see the specialist team, others may not attend for other reasons – even though they may benefit from the involvement. These complex reasons are reflected in the data. Further analysis is required to explore possible interactions between variables. We will discuss these findings with members of the specialist perinatal mental health team with the aim of interpreting results and drawing up a plan for further actions and research.