MEMORANDUM

To: Daniela Puska

Subject: The Contribution of Social Sciences to Health – Call for evidence

Date: 22 April 2016

Dear Daniela,

Please find below the evidence collected from the British Sociological Association.

Our Members have submitted a wide variety of case studies which have been detailed in the latter part of the document.

Yours sincerely,

Judith Mudd,
On behalf of the British Sociological Association

Lynn Jamieson, President
British Sociological Association

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The Contribution of Social Sciences to Health

From tokenism to empowerment: progressing patient and public involvement in healthcare improvement

Submitted by – Josephine Ocloo

Abstract

Background - There have been repeated calls to better involve patients and the public and to place them at the centre of healthcare. Serious clinical and service failings in the UK and internationally increase the urgency and importance of addressing this problem. Despite this supportive policy context, progress to achieve greater involvement is patchy and slow and often concentrated at the lowest levels of involvement.

Methods - A selective narrative literature search was guided by the authors' broad expertise, covering a range of disciplines across health and social care, policy and research. Published systematic literature reviews were used to identify relevant authors and publications. Google and hand searches of journal articles and reference lists and reports augmented identification of recent evidence.

Results - Patients and the wider public can be involved at most stages of healthcare, and this can have a number of benefits. Uncertainty persists about why and how to do involvement well and evaluate its impact, how to involve and support a diversity of individuals, and in ways that allow them to work in partnership to genuinely influence decision-making. This exposes patient and public involvement (PPI) to criticisms of exclusivity and tokenism**.**

Conclusions - Current models of PPI are too narrow, and few organisations mention empowerment or address equality and diversity in their involvement strategies. These aspects of involvement should receive greater attention, as well as the adoption of models and frameworks that enable power and decision-making to be shared more equitably with patients and the public in designing, planning and co-producing healthcare.

Fit to practice? LGBT inclusion in health and social care education and accreditation

Submitted by – Zowie Davy

Inequalities for lesbian, gay, bisexual and transgender (LGB and T) people in UK social care, health and medicine are increasingly well documented. For example, within the past two months, two new research studies have appeared that provide further evidence on the inequalities experienced by LGB and T service users, patients and staff in social care and health.

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Stonewall's 'Unhealthy Attitudes' report on the treatment of LGB and T people in health and social care found that 'whilst the majority of health and social care staff want to deliver the best possible service to LGBT people, LGBT bullying and discrimination are often left unchallenged, and there is too little understanding of LGBT health concerns across vital health and social care services' (Somerville, 2015 p.5).

PACE's five-year study into LGB and T mental health shows that 'participants reported that a lack of awareness and training means responses from medical or professional staff can feel inadequate' (Nodin et al, 2015 p.5).

So, in this context, this study into LGB and T curriculum and accreditation inclusion in social care, health and medicine, provides an important addition to the body of evidence. By examining what students learn and professional accreditation standards, the research has the potential to explain why LGB and T people are not receiving the care and support they deserve and are entitled to.

Method

The authors used a mixed methods approach for this small-scale qualitative study.

Face to face and telephone interviews lasting around an hour were carried out with members of university teaching staff in one large region in Britain. The researchers sent out emails to 360 staff teaching on social care, health, medicine, social work or psychology courses in 6 universities in the region. Only 10 educators responded from 5 universities, giving a response rate of 3 percent.

The semi-structured interview schedule covered question about whether they thought:

- teaching was informed by accreditation policies;

- how important LGBT issues were for the course they taught;

- LGBT content in their and colleagues' courses; and

- whether inclusion or exclusion of LGBT issues was a 'personal pedagogical choice'.

Transcripts were thematically analysed by two researchers.

A 'thematic discourse analysis' of 18 UK social care, health and medical accreditation policies from the key professional colleges and councils was also conducted. These included the General Medical Council, Royal College of Nursing and Health Care and Professional Council (which covers social care and social work). These policies are used to set standards about knowledge, skills and behaviour that students must have when they graduate and start practicing.

Data from the accreditation policies was thematically analysed in relation to the research questions.

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The themes from the two datasets were then mapped together and developed into final themes that all members of the research team agreed on and that they believed reached 'conceptual generalisabilty.'

Findings

The reseachers developed the following three themes and sub-themes from analysis and mapping of the accreditation policies and interviews:

Values and competencies

- Impact of teaching LGBT issues

- Professional competencies

- Equality, diversity and ethics

- Patient centredness

Curriculum time and space

- Time

- Clinical practice

- Pedagogical commitment

- School level commitment

Resistances by students and colleagues

- Knowledgeability

- Student choices

- Homophobia and transphobia

- Balancing curriculum and cultural differences

The researchers highlighted issues with administrative, 'broad deposit-making gestures' towards covering equality and diversity in health and social care accreditation and curricula which can marginalize the social complexities for LGB and T people. They note that

'Despite the multiple accreditation policies in place and gestures towards LGBT content it tends not to be "naturally integrated" throughout the courses we considered.'

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In the classroom, the researchers found that

"sometimes teachers were anxious about including LGBT curricula content because of student responses."

Overall, they found that the inclusion of LGB and T issues in health and social care curricula was effected by the lack of specific focus on LGB and T issues in policies underpinning practice and anti-discriminatory work.

Conclusion

The authors concluded that;

"The evidence presented suggests that LGBT content teaching is often challenged at various points in its delivery…these include the lack of collegiate, colleague and student cooperation."

They also concluded that

"non-hostile and open healthcare environments for LGBT patients are required and need to be created, in part, by knowledgeable teachers equipped to engage with the richness and complexity of LGBT patients' lives."

Strengths and limitations

This study provides important insight into the to extent which accreditation policies of the major social care, health and medical councils and colleges are inclusive of LGB and T issues and thereby ensure that practitioners are fully competent to practice in an anti-discriminatory, person-centred way.

The authors are clear about the limitations posed by the very small response rate to their call for interview participants from universities in one UK region and they also note that they are not intending to generalize the findings.

The findings are also only representative of one UK region, the broad characteristics of which are not given. The universities are also not described in any way. This decision may have been based on ethical concerns about identification, but some brief information about the setting would have been helpful.

The interview part of the study was presented as being an exploratory investigation into the teaching of LGBT issues and what the facilitators and barriers are. So while this part of the study is weaker because of the very small response rate, and any conclusions should be drawn with caution, it provides an initial snapshot of a situation that merits further investigation as the research findings should be of considerable concern.

Despite the limitations of the interviews, the thematic mapping of the two datasets strengthens the findings.

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Summing up

National policy for health and social care determines that it should be person- or patient-centred, with practitioners who are culturally competent and sensitive to the strengths and needs of individuals.

More broadly, practitioners in social care, health and medicine are delivering support to the public, within the context of the Equality Act 2010. As such, these services should be accessible to and effective for LGB and T people.

However, this research suggests that current education and accreditation in social care, health and medicine may not be supporting students and practitioners to fully understand LGB and T issues or even to become competent or fit to practice with LGB and T people.

This situation needs urgently addressing if legal obligations under the Equality Act 2010 are to be fulfilled and, more importantly, all LGB and T people are to experience good quality, empowering, non-discriminatory, person-centred care and support.

If same-sex couples can now legally marry on an equal basis with opposite-sex couples, then all LGB and T people should be able to access safe, supportive social care and health services with confident, competent staff. Education and accreditation is one of the first places to start in ensuring that this happens.

Preventing Mental ill-health: informing public health planning and mental health practice

Submitted by - Jennifer Newton

Problem: In all regions of the world, depression is close to the top of the league table of conditions that are associated with the highest years lost to disability. Provision for mental ill-health of all kinds is under-resourced, despite associated costs being substantial: through unemployment, low productivity linked to those unwell but still at work ('presenteeism'), disability benefits, challenges to family life, and costs to the health service. There is much we could do by way of prevention if the social sciences were better applied.

Purpose and social science contribution: I conducted a review to explore what might be done to reduce the incidence of mental ill-health (Newton, 2013), with a focus in particular on depression and the psychoses. That is, what might the implications be if we used all the research we have on all related issues – stressful experience, stigma and labelling, social support, parenting, social disadvantage, social exclusion, coping strategies, as well as biological evidence on inherited susceptibility, personality factors such as optimism, and even diet and exercise. I am still pulling out the implications for practice (eg Newton, 2015).

Impact, and scope for making better use of social science: I focused on four main conclusions about what matters, and the implications for policy and practice: – the importance of feeling loved as child, but particularly, not experiencing a prolonged period of neglect, rejection or abuse; of feeling safe through feeling protected

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from harm, particularly in childhood, but throughout life; feeling valued – that we matter to someone or some thing; and having some control over our lives. While the emphasis was on the psychosocial, the evidence is that the biological and psychosocial influences combine to create vulnerability or resilience (through 'epigenetics'). The old nature-nurture debate is no longer relevant, but continues to cause divisions among those more influenced by one side than the other.

The final chapters, however, demonstrated that the good intentions of policy and practice do not produce the expected benefits to those vulnerable to mental ill-health. Or at least, not to the extent expected. Sometimes they are wholly counter-productive. The explanations are solidly within the social science arena.

I reasoned that it may be partly linked with being identified as needing help, which can be humiliating. Humiliation is a key aspect the stress that can provoke depression. It is partly to do with the difficulties of recruiting and retaining those who most need help long enough to benefit. Their problems of engagement are linked to the problems that caused them to be vulnerable. Other concerns are due to bringing together people who have similar difficulties in an attempt to help them, but which further reinforces their image of themselves as of low worth. Or labelling: the consequences for someone receiving a diagnosis of schizophrenia can be worse that the effect of the symptoms: on relationships, employment opportunities, self esteem.

Culture, communities and politics all play a role too. How is it that the Netherlands produces an environment so much more conducive to child wellbeing than the UK or USA?

I explored all of these issues, but there is so much more scope to develop these insights, to improve the effectiveness of policy and practice, and to improve the nation's health.

For further information, please see:

Newton, J. (2013) Preventing Mental ill-health: informing public health planning and mental health practice. London: Routledge

Also referenced above:

Newton, J. (2015) Prevention of mental illness must start in childhood: growing up feeling safe and protected from harm Br J Gen Pract 2015 Apr; 65 (633): http://bjgp.org/content/65/633new

Patient Reported Experience Survey Engineering of Natural Text: developing practical automated analysis and dashboard representations of cancer survey freetext answers

Submitted by – Carol Rivas

1. **Problem – outline the issue at stake**

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Patient Experience Surveys (PES) are recognised as important indicators of the quality of health service provision and service improvement priorities. The Cancer Patient Experience Survey (CPES), begun in 2010, is widely acknowledged as the most successful national PES in enabling and embedding service improvement through feedback of responses to its closed questions using a traffic light indicator system. PES also tend to include open-ended questions for respondents to leave freetext comments. CPES for example has three such questions, generating over 70,000 such comments each year. Currently there is no system to efficiently and usefully analyse and report these; conventional thematic analysis takes too long, limiting the usefulness of PES freetext for healthcare service improvements.

2. Purpose – outline the aim of the study

We are developing and validating novel use of 'text engineering' software to provide rapid automated thematic analysis of CPES freetext. The software programme is written to follow the same rules that we use to understand language, and so is sometimes called a form of artificial intelligence. Using the rules, it can group together what it 'understands' to be similar comments. A linked interactive website or 'dashboard' will display results in a summary format that can be drilled down to original freetext by patients and staff alike. The display design will illuminate service gaps.

3. Social Science contribution – detail the specific social science contribution

Our software will process Big Data freetext in almost real time. But our patient advisers wished to ensure their voices would not be lost in the process. So several smaller social science style studies are feeding into the design of the automated analysis. We have asked patients, carers and NHS managers and clinicians to tell us what figures of speech they use when talking about cancer and its treatment. We will also hold large focus groups where patients, carers and NHS staff meet together to negotiate agreement on our website and what information it should contain to optimise healthcare improvements.

4. Impact – detail the impact (including any direct lessons for policy and practice)

Our dashboard will be hosted on the Insight NHS England website, the MacMillan website and other relevant sites. We expect it to facilitate cancer healthcare improvement.

5. Scope for further social science contribution – comment on the scope for even greater contribution in this area if the social sciences were more valued

Our approach is currently being used to improve the Big Data analysis of survey freetext but is producing other rich data, such as information on the types of figures of speech clinicians and patients use. These data are currently of no particular interest to most policy makers but can show, for example, what the different types of people consider as important and how healthcare influences so many intersecting factors.

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6. Details (using the Harvard system of referencing) to the full study

For further information, see http://www.nets.nihr.ac.uk/projects/hsdr/1415615.

The Case Study of Developing Culturally Sensitive Health Policy and Practice for the Chinese Community in Britain

Submitted by –
Ruby C M Chau
Visiting Scholar, Department of Sociological Studies, The University of Sheffield
Sam W K Yu
Associate Professor, Department of Social Work, Hong Kong Baptist University

Theme
Improving outcomes and tackling inequalities

Problem
The Chinese population in Britain has had a low usage rate of the health care services in comparison with other ethnic groups (Chau et al, 2014). Conventional explanations such as language barriers, lack of knowledge of the health care system, and their strong tradition of using Chinese medicine are insufficient in capturing the complexity of their diverse needs and preferences for health care services. Effective approaches to the provision of culturally sensitive health care services are yet to be developed.

Purpose
To address these problems, we have conducted a number of studies with the support of Chinese service providers in different cities (Chau, 2007; Yu, 2000). The main purposes are 1) to explore the diverse needs and preferences of health care services among Chinese people; 2) to search for effective approaches to the provision of culturally sensitive health care services; 3) to draw relevance of these approaches to the development of culturally sensitive services for other ethnic groups.

Social Science Contribution
These studies have contributed to the understanding of the relevance of traditional ideologies (such as Confucianism and Taoism) to health care beliefs of contemporary Chinese people in Britain. They have explored the different patterns among Chinese people in the use of traditional and Western medicine, including the selective use of either in different circumstances, combined use of both on the same occasion but for different functions, using one as conceptual framework to understand the other. These findings have enhanced the understanding of concept health pluralism and provided real examples of its application in people's daily life (Chau and Yu, 2004).

Impact
These studies show the complex reasons behind the comparatively low usage rate of health care services among Chinese people. They demonstrate the need for better understanding of their pluralistic health needs and preferences for health care services. Practical suggestions include the use of a 'culturagram' in the assessment

of health needs (Chau and Yu, 2010) and a new paradigm for welfare to encourage user participation (Chau, et al 2011). Four approaches to culturally sensitive health care have been proposed, namely the Mainstream Services (MS), Shared Cultural Knowledge (SCK), Diversity Based (DB) and Knowledge Transfer (KT) (Chau et al 2014).

Scope for further social science contribution

The mixed use of different medicines (e.g. traditional, complementary and modern) is not unique to Chinese people. The study of pluralistic health needs and preferences and search for culturally sensitive health care services should be extended to people of different social and cultural backgrounds. An action research would be useful to review the effectiveness of the practical suggestions and four approaches to culturally sensitive health services identified in previous studies. Further clinical and empirical research on the different patterns of mixed use of different medicines would provide evidence for their effectiveness for curing diseases and promoting health.

Details to the full study

For details, please see:

1. Chau, C. M.; Yu, W. K. and Law, S. F. (2014). Culturally Sensitive Health Care Services for Chinese People in Britain. *Journal of Ethnic and Cultural Diversity in Social Work,* 23(3-4), pp. 256-270.
2. Chau, C. M. and Yu, W K (2012). Understanding the Diverse Health Needs of Chinese People in Britain and Developing Culturally Sensitive Services. *Journal of Social Work*, 12, pp. 385-403.
3. Chau, C. M.; Yu, W. K. and Tran, L. (2011). The Diversity Based Approach to Culturally Sensitive Practices. *International Social Work*, 54, pp. 21-33.
4. Chau, C. M. and Yu, W. K. (2010). The Sensitivity of United Kingdom Health-care Services to the Diverse Needs of Chinese-origin Older People. *Ageing and Society*, 30(3), pp. 383-401.
5. Chau, C. M. and Yu, W. K. (2009). Cultural Sensitive Approach to Health and Social Care: Uniformity and Diversity with the Chinese Community in Britain. *International Social Work*, 52(6), pp. 773–784.
6. Chau, C. M. (2008). *Health Experiences of Chinese People in the UK, A Racial Equality Foundation Briefing Paper*. London: Race Equality Foundation.
7. Chau, C. M. (2007). *The Involvement of Chinese Older people: Aspirations and Expectations*. York: Joseph Rowntree Foundation.
8. Chau, C. M. and Yu, W. K. (2004). Pragmatism, Globalism and Culturalism: Health Pluralism of Chinese People in Britain. In I. Shaw and K. Kauppinen, eds., *The Definition and Construction of Health and Illness: European Perspectives.* Aldershot: Ashgate Press, pp. 65-79.
9. Chau, C. M. and Yu, W. K. (2000). From Double Attachment to Double Detachment: Chinese Older People in Britain. In M. Nolan, L. Warren and A. Warne, eds., *Care Services for Later Life: Transformation and Critiques*. London: Jessica Kingsley Publishers, pp. 259-272.
10. Yu, W. K. (2000). *Chinese Older People: a Need for Social Inclusion in Two Communities.* York: Joseph Rowntree Foundation.

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