

Institution: The Open University		
Unit of Assessment: A3 Allied Health Professions, Dentistry, Nursing and Pharmacy		
Title of case study: Optimising clinical encounters with people with diabetes: using appropriate language to support emotional wellbeing		
Period when the underpinning research was undertaken: 2000-2019		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Prof Cathy Lloyd	Professor of Health Studies	1998-Present
Period when the claimed impact occurred: 2013-2020		
Is this case study continued from a case study submitted in 2014? N		
<p>1. Summary of the impact</p> <p>The use of empowering and non-judgemental language is vital for the effective care and psychosocial wellbeing of people with diabetes. Prof. Lloyd's research concerning culturally and linguistically appropriate language for use with these individuals has led to impacts on policy; practitioners; and awareness and understanding including:</p> <ul style="list-style-type: none"> • a new set of recommendations on the use of language in clinical encounters endorsed by NHS England and Diabetes UK; • parallel recommendations in India and Canada and an information leaflet in Kenya; • raised awareness among healthcare professionals and people with diabetes; • a changed approach to training of healthcare professionals. 		
<p>2. Underpinning research</p> <p>This impact case study is underpinned by a large body of research conducted by Prof. Lloyd on the psychological well-being of people with diabetes and the importance of appropriate language in the clinical encounter which promotes confidence with diabetes self-management. The significance of these psychosocial factors has been widely observed to be vital for long-term physical health and reducing the risk of life-threatening diabetes complications.</p> <p>Lloyd's research takes an inclusive and empowerment approach which recognises the importance of culture-dependent identification of individuals with diabetes who require support to optimise self-management and address their emotional well-being, particularly those whose main language is not written but only spoken [O1, O2]. Research funded in 2005 by Diabetes UK was conducted by Lloyd in a hospital setting in an area where a high proportion of the population are from ethnic minority backgrounds with high levels of deprivation and low literacy levels and where >6,000 individuals attended diabetes clinics. Culturally appropriate ways (both written and audio methods) to assess emotional status (depressive symptoms and overall wellbeing) as well as knowledge of and challenges with diabetes self-management (using the Michigan Revised Diabetes Knowledge Scale; RDKS) were developed through focus groups and rigorous pilot testing with people from Pakistani and Bangladeshi backgrounds [O1, O2].</p> <p>Lloyd's research findings were replicated in a study in Bangladesh, which demonstrated the acceptability of the same methods of collecting data on diabetes knowledge and self-management in people with Type 2 diabetes attending secondary care facilities in both urban and rural areas [O3]. Building on her work, Lloyd subsequently developed a modified 'True-False' version of the RDKS which was easier to complete and demonstrated favourable psychometric properties when compared with the original scale and has now been utilised in a number of other research and practice settings [O4]. Lloyd's expertise was recognised in 2012 when she was invited to collaborate on research examining satisfaction with clinical encounters with GPs for minority ethnic groups (from Bangladesh, Pakistan and India) living in the UK with varying literacy skills [O5]. The research was part of the National Survey of GP Satisfaction funded by the National Institutes of Health Research (PI Professor Martin Roland, Cambridge University). It demonstrated that the availability of a concordant language was significantly associated with greater patient satisfaction in their clinical encounters with their GP [O5].</p> <p>Lloyd's UK cross-cultural work continued through her leadership of a large multi-national study (supported by a grant from the Association for the Improvement of Mental Health Programmes),</p>		

the International Prevalence and Treatment of Diabetes and Depression (INTERPRET-DD) study [O6]. In addition to characterising the correlates of emotional distress in people with type 2 diabetes in different settings, this research programme (involving approx. 3,000 participants) included a focus on professional practice, developing clinical assessment questionnaires that were culturally and linguistically optimised for each of the 14 countries involved. For example, this work established that words such as ‘depressed’ or ‘anxious’ had different connotations in different cultural groups and languages which could adversely impact the outcomes of any clinical interventions in which they were involved [O6]. **Lloyd** brought this theme to her research in 2017, which aimed to understand how the language used might influence the emotional well-being of people with diabetes. Her findings highlighted the negative impact of stigmatising language on the communication between people with diabetes and health care professionals [O7].

3. References to the research

All cited outputs can be made available on request.

- O1. Lloyd, C.E.**, Sturt, J., Johnson, M.R.D., Mughal, S., Collins, G., and Barnett, A.H. Development of alternative methods of data collection in South Asians with Type 2 diabetes. *Diabetic Medicine* 2008;25(4):455–462. <https://doi.org/10.1111/j.1464-5491.2008.02401.x>. Blind peer reviewed.
- O2. Lloyd, C.E.**, Roy, T., Begum, S., Mughal, S., and Barnett, A.H. Measuring psychological well-being in South Asians with diabetes; a qualitative investigation of the PHQ-9 and the WHO-5 as potential screening tools for measuring symptoms of depression. *Diabetic Medicine* 2012; 29(1): 140–147. <https://doi.org/10.1111/j.1464-5491.2011.03481.x>. Blind peer reviewed.
- O3.** Roy, T. and **Lloyd, C.E.** Development of audio methods of data collection in Bangladesh. *Diversity and Equality in Health and Care* 2008; 5(6): 187-98. <https://diversityhealthcare.imedpub.com/development-of-audio-methods-of-data-collection-in-bangladesh.php?aid=2141>. Blind peer reviewed.
- O4.** Collins, G.S., Mughal, S., Barnett, A.H., Fitzgerald, J., and **Lloyd, C.E.** Modification and validation of the Revised Diabetes Knowledge Scale. *Diabetic Medicine* 2011; 28(3):306-310. <https://doi.org/10.1111/j.1464-5491.2010.03190.x>. Blind peer reviewed.
- O5.** Burt, J., **Lloyd, C.E.**, Campbell, J., Roland, M., and Abel, G. Variations in GP–patient communication by ethnicity, age, and gender: evidence from a national primary care patient survey. *BJGP* 2016; 66(642): e47-e52. <https://doi.org/10.3399/bjgp15X687637>. Blind peer reviewed.
- O6. Lloyd, C.E.**, Nouwen, A., Sartorius, N., Ahmed, H.U., Alvarez, A., Bahendeka, S., et al. on behalf of the INTERPRET-DD Investigators. Prevalence and correlates of depressive disorders in people with type 2 diabetes. Results from the International Prevalence and Treatment of Diabetes and Depression (INTERPRET-DD) Study; a collaborative study carried out in 14 countries. *Diabetic Medicine* 2018; 35: 760-769. <https://doi.org/10.1111/dme.13611>. Blind peer reviewed.
- O7. Lloyd, C.E.**, Wilson, A., Holt, R.I.G., Whicher, C., and Kar, P. Language matters; a UK perspective. *Diabetic Medicine* 2018; 35(12): 1635-1641. <https://doi.org/10.1111/dme.13801>. Blind peer reviewed.

This research programme for [O1, O2, O5, O6] was supported by the following peer-reviewed grants:

Lloyd, C.E. (PI) The development of alternative modes of data collection in ethnic minority populations with diabetes, Diabetes UK, 2005-2007, GBP29,554.

Lloyd, C.E. (PI), Identifying psychological problems in South Asians with diabetes, Diabetes UK, 2010-2011, GBP14,735.

Lloyd, C.E. (Co-I), Pre-conception care for women with type 1 or type 2 diabetes: what are the facilitators and barriers to uptake? NIHR Health Technology Assessment, 2014, GBP211,000.

Lloyd, C.E. (PI), Dialogue on Diabetes and Depression: Development of an updated and annotated bibliography, 2011 & INTERPRET-DD: International Prevalence and Treatment of Diabetes and Depression in 20 countries, Association for the Improvement of Mental Health Programmes, 2013, approximately GBP63,000.

4. Details of the impact

Lloyd's research leadership in the field of optimising clinical encounters for people with diabetes on the basis of cultural awareness and language selection has led to impacts in the areas of **policy; practitioners;** and raised **awareness and understanding**. Beneficiaries include health care professionals and people living with diabetes.

Initial impact came from the development of culturally appropriate questionnaires for the assessment of depressive symptoms and diabetes self-management efficacy. A wider understanding of the importance of taking a holistic approach (including language and culture) to care became evident in the clinical environment where the research took place as well as more widely. For example, the former leader of the Michigan Diabetes Research Team states in his testimonial: “[...] *there is continued interest and demand for the RDKS. Since 1 August 2013, I have received numerous inquiries from clinicians, researchers and academics requesting copies and permission to use the questionnaires in a range of diabetes populations. The scale assists health care professionals initiate conversations to identify gaps in understanding or difficulties with self-care. They have also found true/false format to be particularly useful for patient populations with low literacy*” [C1].

Impact on policy: publication of position statements by health care organisations

Lloyd's well-established research profile and her advancement of the importance of language and cultural awareness led to her invitation in 2017 to join a newly founded (by NHS England) Language Matters Working Group which directly draws upon her extensive research. The National Specialty Advisor for Diabetes, NHS England, states: “*Thank you for taking the lead in developing and launching our Language Matters Position Statement, including both the position statement itself but also conducting and publishing the research which formed the evidence base for our work. These recommendations have been crucial for encouraging the much needed changes to clinical practice and have been widely welcomed as evidenced by both your post-launch survey and the positive response we have received at UK-wide events, such as the South Asian Health Foundation and Diabetes UK conferences*” [C2]. The NHS Language Matters Position Statement details a new set of recommendations for health practitioners on the language to be used in clinical encounters with people who have diabetes [C3].

In 2018, the Position Statement was endorsed and launched nationally by NHS England and Diabetes UK, both online and via the annual Diabetes UK health professionals conference where **Lloyd** presented the work (approximately 500 attendees) and led two workshops for both healthcare professionals and people with diabetes. It was the most downloaded document from the NHS England website in the week of its launch (over a thousand downloads). Direct links to the download website sent specifically to the Clinical Commissioning Groups (representing 3,138 health care professionals) yielded a further 102 document access requests. The visibility of the Position Statement was further enhanced via other channels for diabetes care professionals such as the Juvenile Diabetes Research Foundation [C4, pp.1-2]. The philosophy of the Language Matters Group has been taken onboard by Obesity UK, with a Joint Consensus Statement on the language used for people over-weight or with obesity published in May 2020 [C5, p.2]. As the National Specialty Advisor for Diabetes, NHS England commented: “*Beyond this UK Position Statement, I am grateful for your help with the version more suited to the Indian population [...] and your help with the Language Matters version we have developed for Obesity*” [C2].

Raising awareness and reducing the stigma surrounding diabetes and depression outside the UK

The published guidelines were replicated (in collaboration with **Lloyd**) in the Language Matters Position Statement for people with diabetes in India (endorsed by the President of the International Diabetes Federation) and informed those developed in Canada, and have been translated into Tamil, Hindi, Spanish and French, all of which are publicly available [C6, p.1].

Lloyd has leveraged her research in the UK and her experience of leading the development of the NHS Language Matters position statement to adapt the UK Position Statement for use in Kenya. Although Kenya is a very different socio-economic and cultural context compared to the UK, similar differences in the use of language to describe symptoms of both diabetes and depression are apparent at the community level. Furthermore, stigma around mental health exists and remains a substantial barrier to reporting mental health problems, leading to poorer quality of life among people with diabetes and their families. **Lloyd** has conducted field studies in rural Kenya to design and evaluate a revised Position Statement on diabetes and depression. The aim has been to raise awareness and reduce the stigma surrounding these two conditions, so as to increase access to appropriate services and improve psychological wellbeing for people with diabetes or depression. Her consultations with community members demonstrated wide support for the development of information leaflets which could address this. For example, a Community Leader stated: *“You are doing a worthy cause for the community. Through the activities you are doing many problems will get a solution on the ground before they reach a level where they cannot be addressed”*. An evidence-based, culturally appropriate information leaflet has been written and evaluated by stakeholders including service users, community health volunteers, health care practitioners working in rural communities and secondary care services [C7, p. 24].

Impact on health care professionals and people with diabetes

Post-launch, the NHS England Position Statement was evaluated by health care professionals including doctors, nurses, dieticians and psychologists via a survey [C8, pp.1-4]. Of the 91 responses, 97% of individuals were aware of the Position Statement [C8, p.5], 78% had downloaded the document [C8, p.6] and 82% said they found it useful [C8, p.9]. In the evaluation the common ways it was reported to have been used were as guidance for staff, discussion in team meetings and to improve communication with those they encountered during practice [C8, pp. 7-8]. A consultant clinical psychologist working with adults with diabetes, for example said: *“It’s increased my sensitivity in this area as well as given me ideas on how to make a difference”* [C8, p.7]. A diabetes clinical nurse specialist in training also mentioned it helped her change *“the relationships with some of the people living diabetes, allowing empowering them”* [C8, p.13].

A participant in a separate survey of people with diabetes said: *“This is not about policing the language used by people with diabetes. It is about healthcare professionals understand how the language (they) use can impact on us”* [C9, p.7]. Another respondent said *“If a medic in a hospital wants to force a patient to accept treatment against their will they just speak in an authoritative tone and feign exaggerated shock or disapproval to the patient’s choice of treatment/non-treatment. This needs to stop”* [C9, p.7]. Half of those who completed the survey had found the statement through the Diabetes UK website (the foremost place for locating information for people with diabetes) and two-thirds had read the statement. Feedback included recommending wider dissemination and the use of video to promote it further [C9, pp.6-7].

In 2020, **Lloyd** subsequently led two webinars on Language and the Emotional Wellbeing of people with diabetes [C10] both of which supported the professional development of health care professionals but were also available to people with diabetes. In-depth interviews with health care practitioners demonstrated that the Position Statement, along with the webinars, has led to significant changes in practice. For example, a nurse educator reported that they had *“discovered (the) ‘Language Matters’ document, while searching on (the) Internet for ways to authentically construct a simulated consultation with someone with diabetes for training*

purposes [...]. To highlight the central role of competence in communication as well as in physical care activities” [C11, p.6].

A Diabetes Specialist Nurse reported that she started noticing that changes in the way the questions were worded made a difference to patients' responses: *“I think people respond really differently to any other way of phrasing talking about any of these issues and it shows there is a way out, too [...] I notice people pause as if they feel more heard and less judged – they will discuss more about what issues they have, causes. Much more than ‘I know I am overweight, and I need to lose it’, it seems to open the conversation up properly” [C11, p.2].* A Community Diabetes Specialist Nurse said: *“Often I would hear, this patient won't show up/won't take advice/won't change, and I would wonder why? So, I normally say something like: I notice it has been a while since we have met, is it OK if we talk about what's been happening for you? Something like that. Then the whole consultation changes as it becomes about the person, not about my agenda” [C11, p.3].*

A Diabetes Specialist Dietitian working in an NHS Trust said that during a new virtual education programme developed in lockdown, her team received feedback that the participants felt judged and blamed. The team then discovered the Language Matters document and circulated this within the practice and began using it in their efforts to be more empathetic and non-judgmental with their patients: *“Awareness of language in diabetes has helped to create an even greater awareness of language in everyday life and its potential to damage or upset, especially at the moment with Covid” [C11, p.8].* Although the focus of these webinars was diabetes, impact can be seen in other specialties. The Policy Research Officer for the European Association for the Study of Obesity said *“in my new position now at EASO person-first language was explained and encouraged from day 1 [...] absolutely I have changed the way I use language around chronic diseases both professionally and in my personal social life” [C11, p.3].*

5. Sources to corroborate the impact

C1. Testimonial letter: The former leader of the Michigan Diabetes Research Team, 30 Oct 2020.

C2. Testimonial letter: The National Specialty Advisor, Diabetes, NHS England, 21 Dec 2020.

C3. Language Matters Position Statement.

C4. Juvenile Diabetes Foundation guidance.

C5. Obesity UK Website & Obesity UK Language Matters Booklet

C6. LanguageMatters.com (<https://www.languagemattersdiabetes.com/>).

C7. Evidence of impact in Kenya:

- Language Matters leaflet from our collaboration in Kenya.
- Interview transcript with a Community Leader.

C8. Survey of health care professionals evaluating the Position Statement.

C9. Survey of people with diabetes evaluating the Position Statement.

C10. Webinars on Language and the Emotional Wellbeing of people with diabetes:

- Webinar: Language Matters; supporting emotional health in people with diabetes hosted by The OU. <https://doi.org/10.21954/ou.rd.13712869.v1>
- Webinar: Language matters: the impact on people living with diabetes hosted by The Association of British Clinical Diabetologists in collaboration with service users as well as health care professionals. <https://doi.org/10.21954/ou.rd.13712902>

C11. Interviews of health care professionals reporting impact of webinar.