Patient and Public Involvement in the reorganisation of diabetes services in Case Site 3 (CS3)

Culturally sensitive healthcare for the BME community

Introduction to CS3

CS3[1] is a large urban town situated in the South of England with a population of around 200,000. It is ethnically diverse with a large black and minority ethnic (BME) population (around 40.6% of total population[2]) with significantly higher populations of Pakistani, Bangladeshi, Indian and African Caribbean compared to its regional neighbours[3]. It also has comparatively higher than average mixed ethnic and white Irish populations and increasingly large minority groups from Eastern European areas, such as Poland. It is a generally young person's town, having a higher average percentage of people under the age of sixteen than within its region[4], with a higher than average birth rate but also a rising older age group population[5]. The Pakistani and Bangladeshi populations are projected to rise by approximately fifty per cent between now and 2030[6]

Background to reconfiguration of diabetes services

Services for diabetes are in the process of being reconfigured to provide more 'patient friendly' services delivered, in most part, in the community. Historically there was perceived an over reliance on secondary services for diabetes and this was viewed as both inconvenient for patients as well as an inefficient use of NHS resources. The model for delivering diabetes services would be through levels of care, from basic and enhanced GP services [level 1 and 1a} to intermediate community [level 2] and specialist care [level 3]. Patients would be

---

[1] CS3 used for confidentiality

[2] HWBB Strategy 2012-17

[3] Compared to others within the case study site's Area Health Authority

[4] ONS 2007

[5] Much of this data derived from Census 2001 as data from Census 2011 not available at time of writing. Other statistical data extrapolated from ONS and Health and Lifestyle Survey as well as other statistical data listed in references.

[6] *'CS3'* Population Projections by age and ethnicity net nil Migration, Research and Geospatial Information Team, Department of Environment and Regeneration, *'CS3'* Borough Council, 2012.

allocated to the appropriate level based on an assessment of risk. New community integrated multidisciplinary teams are being developed to support patients and supplement care delivered by GPs, including up-skilling primary care practitioners in diabetes care. The multidisciplinary teams include practitioners from primary, secondary, community and social care. The focus of care will be on prevention, early intervention and support for self-care. The main outcomes expected from this reorganisation include a cost saving resulting from a reduction in hospital stays and out-patient appointments as well as improved patient self-care knowledge and patient satisfaction. Increased equity of access, particularly for ethnic minority patients, is also identified as a key outcome from this reorganisation. Planning has been on-going since early 2010 and there has been a draft business case since July 2011. Service specifications have yet to be agreed and it is anticipated that this will not be fully operational until April 2014.

The BME community in CS3

The new service model aimed to address service gaps and unmet needs, including those for Black and Minority Ethnic [BME] groups, who were seen to have a lower uptake on some diabetes services, such as retinal screening[7] as well as having a lack of knowledge and awareness of services[8] One provider reported that GP referral rates for diabetes services were variable for some of the BME community. Diabetes prevalence in the case study site is higher than the national average (6.5% in 2010[9]) though below estimation rates (8.7%) indicating that a large number of the population are not yet diagnosed[10], with the likely possibility that a large number of these would come from the BME community.

National data show that diabetes is six times more common in people of South Asian descent. In this case study site the highest rates of diabetes are in wards with a high concentration of South Asian communities. These wards also have the poorest health outcomes in the Borough.[11]

Involving patients and the public in commissioning diabetes services

---

[7] Personal communication with LTCs commissioner and report from two focus groups held in 2012.

[8] Reports from focus groups (2) held in 2012.

[9] APHO Diabetes Prevalence model 2010

[10] Quality and Outcomes Framework 2010/11 and APHO Diabetes Prevalence Model estimated that there were 1895 adults with undiagnosed diabetes.

[11] JSNA 2010/11 – no JSNA for 2012 available yet

Patient and public involvement in the new diabetes service redesign was tracked for a period of eighteen months [from September 2011 to March 2013]. In July 2011 a business case for the service redesign was in development and implementation was planned for autumn 2011, though they did not get the 'go ahead' for implementation until July 2012[12].

During the redesign there were a variety of methods employed for engaging with patients and the public. The main thrust of engagement appeared to be around assessing needs and developing service specifications. Needs assessment involved reference to data from patients' experience of local services, including patient satisfaction measures from GP practice surveys[13]. This indicated that service users would welcome services closer to home. National patient organisations (such as Diabetes UK) were consulted via a Cluster level diabetes group[14]. On a local level, a diabetes Local Implementation Group [LIG] was set up to plan the implementation and help develop local service specifications. Patient and public membership on this group was limited[15]. A patient representative was eventually recruited by his dietician to sit on the group but did not feel that he had much to offer as much of the planning had been agreed and the agenda was often too clinically specialised and technical[16]. Other engagement activities involved diabetes specialist community providers meeting local patient groups to inform and educate service users and commissioners meeting with local community organisations, specifically those from the BME community, to discuss needs and plans. Focus groups and surveys were also carried out with Bengali speaking and other BME representatives about specific health needs and experiences.

There was little evidence of any wider discussions with patients and the public on the new services. Plans were to commence this in some form once the new services were in place, with the intention of informing the public and receiving feedback[17]. Much of the current reconfiguration work has been around staff development, including up-skilling primary care providers on their new roles and ways of working.

---

[12] This was communicated at a local Diabetes LIG meeting observed in July 2012, the commissioner stating that the business case had been agreed. The Cluster Strategic Plan for integrated care (2012-15) also notes that the business case for diabetes has been approved in 2012. However, following reorganisation in January 2013, the new CCG commissioning lead for long term conditions said [personal communication] that the business case had not been agreed or signed off and that work was still in progress on this and diabetes services should be fully operational by April 2014.

[13] Information obtained from commissioner during interview

[14] Information obtained from commissioner during interview

[15] Local LINks representatives were invited to attend diabetes LIG planning meetings but did not attend

[16] Interview with service user

[17] Information obtained from commissioner during interview

A diabetes service for the local BME community

As part of the diabetes redesign, local healthcare commissioners and providers have been consulting with the BME community about how it could best meet its needs. A number of meetings and focus groups[18] have been undertaken with diabetic service users from the Bangladeshi community within their local community centre, situated in one of the high prevalence of diabetes wards.

Representatives from this community have indicated that they would welcome diabetic services, including advice and guidance on self management, within their community, rather than through their GP or general NHS community health centre. Other main findings of the Bangladeshi community with diabetes included:

- *Limited availability of culturally specific health information in own 'mother tongue' language.*
- *Varying experiences of services for diabetes – some dissatisfaction expressed around GP access, waiting times and follow up care, many feeling that they are not listened to or ignored by their GP.*
- *Responders stressed the importance of their local community centre as 'a hub for information about health and well-being' – particularly for those whose English speaking is poor.*
- *Participants were keen to become involved in the planning of healthcare services for their community but lacked knowledge on how they could do this*
- *There was a general lack of knowledge about how to make a complaint about health services*
- *Some experienced a lack of feedback from health providers when commenting on local services or contributing to surveys*
- *A preference for receiving diabetes care through a 'specialist' practitioner for diabetes rather than a GP.*

Further support for the provision of local, culturally sensitive health services was through a recent survey undertaken with local residents from the BME community[19] where most of

---

[18] Facilitated by the EVOC research team

[19] Interviews with 100 people of Indian, Pakistani, Bangladeshi, Kashmiri and African origin carried out in 2012 by Think-Funding as part of a scoping exercise to assess need of community [personal communication with Director] 88% said that they would attend screening for diabetes, 89% said they would attend local centre for diet and lifestyle advice and health activities.

those who had never been tested for diabetes said that they would attend for testing and lifestyle advice if a clinic was accessible within their local community.

All those consulted in the focus groups regularly attend a local luncheon club at a community centre next door to their local Mosque where they also receive some general advice and guidance on healthy living and undertake a number of health related activities.

The potential to receive specific diabetes and other long term conditions services within this or other similar community setting [i.e. close to their Mosque or Temple] as part of the health service redesign was being considered by NHS CS3. The outcomes from the focus groups informed some of the initial discussion and planning. From speaking to and observing meetings with those responsible for commissioning and providing diabetes services in the community, plans were in place in 2012 for the development of an integrated community based diabetes [and other long term conditions] service for the BME community. This was likely to be funded and staffed by diabetes specialist nurses working with a Bengali speaking support worker and delivered where the community gathered [such as within their own community centre or somewhere similar] and some further investment, in the form of funding extra diabetes specialist staff to work in the community, had been allocated[20].

Indicators for success

It was anticipated that this service would lead to:

- improved access to diabetic services for this group
- increase in screening for diabetes
- better knowledge and understanding of diabetes for this community

Update on progress

The project (to set up the BME service) was planned to commence in September 2012. This was, however, put on hold due to staff capacity [the Bengali speaking support worker left on maternity leave and there was no one to replace her]. This delayed its development for one year and the plan was to set this up within the local BME community centre by September 2013. Service specifications were to be developed through further discussions between the BME community, clinical providers and commissioners and these were being planned for the last quarter of 2012. However NHS re-organisation resulted in the loss of the lead

---

[20] Interview with commissioner and community provider as well as noted from meeting of diabetes LIG.

commissioner in December 2012. The new commissioner is currently in the process of reviewing the business plan and it is not clear if this development will be on the agenda as initially envisaged as service specs had not been defined and funding had not yet been agreed. Recent communication [in March 2013] with one of the community providers suggested that they might be now thinking of providing a community 'drop in service' where health promoting advice and guidance would be offered, rather than the provision of integrated health and social care services as originally considered.

A community hub for providing level two, integrated services for diabetes [and other long term conditions] is also being planned though this will likely be for all LTCs patients[21] rather than specific BME communities.

Frustrated by the slow pace and delays/turnaround by the local NHS in developing the service the director of the BME community centre is now pursuing alternative funding (BIG Lottery) to help develop the centre as a diabetes advice and information centre. He is also planning to build a fitness centre for his community where Bangladeshi and other BME women will be more encouraged to undertake health activities as 'they would be likely to feel more comfortable among their own community'[22].

---

[21] Personal communication with commissioner

[22] Personal communication with director of community centre