

# SUMMARY REPORT

## Understanding attitudes and experiences relating to diabetes in the Kurdish, Turkish, and Turkish-Cypriot communities in North Central London, and exploring engagement approaches as a means of improving awareness and self-management.

### 1 Introduction

Between December 2018 – September 2019, Diabetes UK undertook a project in partnership with the London Clinical networks to explore attitudes and experiences of the Kurdish, Turkish and Turkish Cypriot (KTTC) communities of North Central London (NCL) around diabetes, and to understand how services could better engage and serve these communities to in order to improve health outcomes. This community was selected for a number of reasons:

- Healthcare professionals and diabetes services have had difficulties engaging members of the KTTC communities in the past.
- There are poorer health outcomes among ethnic minorities and in deprived communities (which the KTTC communities are comparatively to the ethnically British population).
- Some limited existing engagement with these communities had shown potential to improve engagement but needed further exploration.

### 2 Methods

Firstly, literature and data available on the KTTC communities and diabetes was reviewed. A variety of healthcare professionals (pharmacists, dieticians, diabetes consultants, GPs) and structured education providers were then interviewed to find out more about their experiences of engaging with the KTTC communities through diabetes. Members of the community and community figures (religious leaders, political figures) were also asked about their attitudes and perceptions of diabetes and their experiences of using diabetes and health services locally.

### 3 Findings

#### 3.1 Literature & data review

- Of the literature available on KTTC communities in London, the majority was more than five years old.
- There was a lack of diabetes-specific data available on the KTTC communities such as prevalence, outcomes or structured education access, attendance and experience.
- Often, ethnicity categories collected are not specific enough to allow distinction between the KTTC communities and other ethnic groups, for example, in primary care and structured education data.
- For these reasons, the conclusions that can be made on the relative prevalence and complication rates in the KTTC communities are limited.

- However, studies in comparable European countries supported the idea that prevalence and outcomes are worse in the KTTC communities.

### **3.2 Qualitative data**

- There was a **low level of knowledge about diabetes generally** including the causes, the differences between type 1 and type 2 diabetes and the **relevance of lifestyle factors** in preventing and managing type 2 diabetes.
- There is **stigma associated with type 1 diabetes** – belief that it is developed due to ‘bad karma’ and that it’s not acceptable to test glucose levels and inject in public.
- The high prevalence of **type 2 diabetes** across the KTTC communities means it is perceived as **inevitable and beyond one’s own control**.
- **Pharmacological and surgical interventions are valued over lifestyle changes** and individuals feel less ownership or accountability for their own health, leaving responsibility to their HCP.
- Different **approaches and attitudes to health in ‘home’ countries** affect KTTC community members’ engagement with NHS diabetes services
- Belief that you **‘get what you pay for’ with healthcare**, and thus state funded healthcare is inferior to private healthcare - many will visit their ‘home’ countries over the summer and see a HCP there so they may receive conflicting advice or miss annual appointments in UK.
- Low awareness of what structured education involves or why it is relevant.
- As **food is central to family life and cultural events**, and eating is typically a **social and communal** activity, it can be challenging for an individual to take control of their own diet.
- Social interactions and the **networks within the community are trusted** as a reliable source of information, but building similar levels of trust with those outside it can be a challenge.
- **Language barriers are a challenge** for both members of the KTTC communities and the healthcare professionals – information can be interpreted differently by the patient to what was intended by the HCP due to cultural factors and a lack of medical knowledge in interpreters can lead to misunderstandings.

## **4 Conclusions**

- NCL KTTC community members’ cultural attitudes and beliefs had a significant influence on their behaviours and therefore need to be taken into consideration in order to improve engagement with these communities.
- Attitudes to diabetes and health more broadly were a barrier to people’s engagement with their care or making necessary lifestyle changes to support prevention of type 2.
- Trust is key; it can be built by showing empathy and understanding to people’s culture and delivering messaging from trusted sources within the community.

## **5 Recommendations**

### **5.1 Use existing community assets within the Kurdish, Turkish and Turkish Cypriot communities, to deliver key messages about diabetes care and prevention.**

**Local community and primary care services should:**

- Seek out and build relationships with trusted figures in the community.
- Work with Diabetes UK and community leaders to recruit and train volunteers as ‘Community Champions’ to support with raising awareness and improving engagement with services.
- Take services, information and messages out to the community in familiar settings (e.g. pharmacies, places of worship, barbers).

**Diabetes UK should:**

- Work with local community diabetes teams to help identify community leaders, and provide Diabetes UK training for speaker volunteers, Community Champions, event volunteers and in delivering the ‘Know Your Risk’ tool.

**5.2 Increase health promotion activity to raise awareness of Type 2 diabetes**

**Local community and primary care services should:**

- Raise the profile of the risk factors, symptoms and complications of diabetes and of availability of support services.
- Share **appropriate messaging** through specific media channels (e.g. local Turkish radio), community groups, community figures, and cultural festivals.)
- Develop **culturally-appropriate resources** for people at risk of and living with diabetes in both Kurdish and Turkish languages and engage the community when changing or developing new services or resources.
- Work with Diabetes UK to deliver ‘**Know Your Risk**’ events in the community.

**Diabetes UK should:**

- Identify areas of need and form **local community peer support groups** for those living with diabetes, working with local services to recruit participants.
- Run **volunteer training** at appropriate / frequented community venues.

**5.3 Provide culturally tailored diabetes structured education programmes, as well as relevant alternatives for those for whom structured education is not appropriate.**

**Local diabetes services should:**

- Understand that not *one size fits all*, so provide different education options.
- Make structured education courses appealing for these communities by:
  - Adapting content to be relevant including foods and cultural practices
  - Improving access by advertising through appropriate channels
  - Running courses at appropriate times and venues
- Recruit people from within these communities to deliver structured education
  - Offer alternatives to structured education by increasing provision and availability of informal education, such as peer to peer education at community centres or places of worship and story-telling and experience based support.

**Local commissioners should:**

- Evaluate and review current structured education offerings based on feedback and demand.
- Commission structured education courses across multiple CCGs (i.e. STP/ICS level) to meet demand and facilitate attendance.
- **Work with providers of structured education courses** to ensure courses are run in appropriate locations (e.g. community centres).
- Consistently collect and evaluate feedback from diabetes services, particularly those that are culturally tailored, to ensure they are on message.

**5.4 Improve the collection and use of data**

**Primary, secondary, community care and providers should:**

- Collect ethnicity-specific data on diabetes prevalence and outcomes.
- Systematically collect data on DNAs for appointments and structured education courses, referrals to secondary care for complications, and adherence to the three treatment targets.
- Consistently collect and use patient experience data, including ethnicity.

**STPs/ICSs should:**

- Collate data across services to build a wider picture across the area to inform commissioning.

**5.5 Equip healthcare professionals with knowledge and awareness of the needs of these communities.**

**Local commissioners should:**

- Ensure that healthcare professionals have appropriate and up-to-date information on local community groups, classes and services to sign-post people to.

**Healthcare Professionals should:**

- Refer patients to culturally appropriate structured education programmes with enthusiasm and a clear explanation as to why they are necessary (see the Diabetes UK '[Improving your diabetes knowledge](#)' information prescription to aid these conversations).

**General practice managers should:**

- Facilitate sessions for Kurdish and Turkish speaking healthcare professionals to share their cultural experience and tips for working with these communities.
- Ensure all healthcare professionals in the practice have access to appropriate and up-to-date information on local community groups and classes to signpost people from this community to. Where this is not available, work with local commissioners to identify such services.

**6 Key messages for healthcare professionals**

**6.1 Addressing language barriers to ensure that messages are correctly conveyed**

- Use the NHSE [language matters guidance](#) and consider the way you communicate, especially when relaying information to an interpreter.
- Use clear and consistent messaging - highlight the seriousness of diabetes and that the patient has the ability to take control and make a difference.
- Use ways of communicating that are suited to those with lower health literacy or who are less engaged, such as colour coded results or pictograms.

**Diabetes UK should:**

- Work with Turkish and Kurdish speaking volunteers to develop culturally appropriate materials in Turkish and Kurdish languages.

**6.2 Understanding and awareness of (cultural) attitudes to health in these communities to ensure effective communication**

- Recognise that it is common for patients from these communities to go away for extended periods over the summer to visit friends and family in 'home countries'.
- Be aware that patients may receive conflicting health information advice when away.
- Do not schedule appointments for over the summer if a patient tends to be away.
- Invite patients to appointments by phone in order to explain the reason / need for the appointment and negotiate a time that works.

**6.3 Understanding of the significance of family structures, including the gender roles**

- Understand that family is likely to be involved in a patient's care and will therefore need to be involved in any associated decisions about their care.
- Welcome family to attend appointments and encourage them to attend structured education sessions to raise and spread awareness.

**Service providers should:**

- Recognise that women are likely to be deciding what their household eats.
- Understand that in some communities, women do not go out unaccompanied, and therefore accommodate partners/chaperones at education courses.

**Explore how women could be better targeted by diabetes services through perinatal services.**

**Diabetes UK should:**

- Partner with schools to raise awareness in children and target female care-givers at daily drop-off and collection (e.g. through fundraising activities).
- Further explore the structures of families and how this affects decision making.

**Read the full report [here](#).**