

Making the most of primary and community services: what works for BAME people with long-term conditions? Research Summary

BASHIR, Nadia <<http://orcid.org/0000-0002-1384-4849>>, DAYSON, Christopher <<http://orcid.org/0000-0003-2402-1183>>, MCCARTHY, Lindsey <<http://orcid.org/0000-0002-5114-4288>>, CHOWBEY, Punita <<http://orcid.org/0000-0001-8400-468X>> and ISMAIL, Mubarak <<http://orcid.org/0000-0001-6601-9781>>

Available from Sheffield Hallam University Research Archive (SHURA) at:

<http://shura.shu.ac.uk/26881/>

This document is the author deposited version. You are advised to consult the publisher's version if you wish to cite from it.

Published version

BASHIR, Nadia, DAYSON, Christopher, MCCARTHY, Lindsey, CHOWBEY, Punita and ISMAIL, Mubarak (2016). Making the most of primary and community services: what works for BAME people with long-term conditions? Research Summary. Project Report. Sheffield Hallam University.

Copyright and re-use policy

See <http://shura.shu.ac.uk/information.html>

Making the most of primary and community services: what works for BAME people with long-term conditions?

Research Summary

December 2016



Making the most of primary and community services: what works for BAME people with long-term conditions?

Research Summary

Author(s):

Nadia Bashir

Chris Dayson

Lindsey McCarthy

With

Punita Chowbey

Mubarak Ismail

December 2016

Acknowledgements

This research was undertaken by a team from the Centre for Regional Economic and Social Research (CRESR) and Centre for Health and Social Care Research (CHSCR) at Sheffield Hallam University, on behalf of NHS Nottingham Clinical Commissioning Group. The research would not have been possible without the commitment of 86 research participants from across the City of Nottingham or seven local voluntary and community organisations that facilitated their participation:

- Nottingham Chinese Welfare Association
- Asian Women's Project
- Afro-Caribbean Women's Group (men welcome), Queens Walk Centre
- Gambian Community Centre
- African focus group (organised and delivered with Self Help UK and City CCG)
- The Signpost to Polish Success
- Indian Community Centre Association
- Kemet FM
- Radio Faza
- BAME Outreach and Development Worker for Self Help UK

The Research Team would also like to thank representatives of the wider public, voluntary and community sectors who have given up their time to contribute to the study. We are particularly grateful to members of the Research Steering Group - Rachel Illingworth, Dawn Jameson and Dr Manik Arora - for their on-going support for the study. The study had NHS research governance approval from Nottingham University Hospitals NHS Trust (Ref: 15RS004), NHS Nottingham Clinical Commissioning Group (Ref: 300615) and Nottingham CityCare Partnership.

Contact information

For the Research Team

Name: Chris Dayson
Senior Research Fellow

Address: Unit 10 Science Park
City Campus
Howard Street
Sheffield
S1 1WB

Tel: 0114 2253539

Email: c.dayson@shu.ac.uk

For NHS Nottingham City CCG

Name: Rachel Illingworth
Head of Research and Evaluation

Address: 1 Standard Court
Park Row
Nottingham
NG1 6GN

Tel: 0115 8839556

Email: rachel.illingworth@nottinghamcity.nhs.uk

Introduction

This report is a summary output from an exploratory research study into the **uptake of primary and community diabetes and respiratory long-term conditions services in Black Asian and Minority Ethnic (BAME) communities in Nottingham City**. The study was commissioned by NHS Nottingham City Clinical Commissioning Group ('the CCG') and undertaken by a team of researchers at Sheffield Hallam University.¹

Nottingham City has a **large BAME population** which accounts for just over one third (35 per cent) of the total population, having increased from just under a fifth (19 per cent) in 2001. Although, overall, BAME residents are less likely than non-BAME residents to report poor health, this is due to the younger age profile of BAME residents, and masks an underlying trend amongst older BAME residents (aged 50+) which indicates they are **more likely than non-BAME residents of the same age to report poor health**. These trends mean long-term condition support services for these communities are important and will grow in importance in the future. As such, the CCG commissioned the study to inform how they can best work in partnership with local BAME communities to increase the uptake of community and long-term conditions services in Nottingham. In particular, they wanted to **better understand the barriers and enabling factors from the perspective of BAME communities** to support the development of effective commissioning strategies that meet their needs and promote and support increased service uptake.

The study was framed around four research questions:

- What are the **blocks and barriers** to people from BAME communities with long-term conditions accessing and taking up existing long-term conditions services?
- How should the CCG, GP practices and service providers **engage with BAME communities most effectively**, including through an asset-based approach?
- What **changes need to be made** to the way services are delivered?
- What are the **next steps for commissioners** to support a sustained increase in uptake of long-term conditions services by BAME communities?

The study was undertaken in two phases between April 2015 and September 2016:

- **Phase 1** was an evidence review, covering UK and international literature and including published academic papers and a wider body of 'grey' material from policy and practice. Secondary data were analysed to provide contextual information and to inform subsequent phases of the study.
- **Phase 2** involved in-depth qualitative research to explore the local context further and identify what needs to be done differently to encourage increased uptake. 69 in-depth qualitative interviews were undertaken with BAME service users from across the City of Nottingham along with 17 stakeholders from the across the local NHS, its local statutory partners and the local voluntary and community sector.

This report provides a summary of the key findings from the research. It aims to provide the CCG and its partners with a **better understanding of the barriers, enabling factors, and best practice associated with the delivery of long-term conditions services to people from BAME communities**, with a view to supporting the development of workable solutions that encourage greater uptake of these services in the future.

¹ The Centre for Regional Economic and Social Research (CRESR) led the research with support from the Centre for Health and Social Care Research (CHSCR)..

Key findings

The research identified findings under eight key themes.

Language and communication

- Poor English language skills lead to low uptake of community and long term conditions services.
- People in contact with health professionals who spoke their first language accessed services with greater ease.
- Experiences of using NHS interpreters were positive.
- There was considerable reliance on family members to act as interpreters and translators of health information.
- All health correspondence was provided in English which meant that participants with low English literacy relied on family members to help them.

Awareness and understanding

- There was a significant knowledge gap around the symptoms and management of diabetes and asthma.
- Gaps in knowledge were explained by a lack of available information before and after diagnosis.
- People had more confidence in managing their condition if they had attended educational courses such as Juggle.
- Other useful channels for learning about a health condition included self-research, television, community radio, and health leaflets/pamphlets.

Provision of services

- Satisfaction with the flexibility and convenience of appointment times and locations for services and educational programmes was mixed.
- Some people spoke positively about their experience of making an appointment but others encountered difficulties at their local surgeries.
- People were keen to attend educational classes but struggled to travel there if they were not within easy reach of their homes.
- Services were more readily taken up when the timings fitted with people's daily commitments.
- Continuity of staff made a difference to patient satisfaction and willingness to engage with services.
- People were positive about services if they had been attentive to specific cultural needs.

Marketing and publicity

- Translated health information on diabetes and respiratory conditions was not offered to the majority of the people in our study in their main languages.
- However, translated materials proved ineffective where patients were illiterate in their first language and health materials alone were not seen as enough to convey complex health information.
- Face-to-face contact, including the Juggle Diabetes Service, along with outreach workers, and speaking with others living with that condition, was a valued method of learning about the management of long-term conditions for many participants.

Religious and cultural barriers

- The role of religion in participants' day-to-day lives varied: from playing no role at all to a very significant one.
- Vast amounts of 'faith' and 'trust' were placed in god as providing support above and beyond assistance of any other kind.
- Some people remain poorly educated in religious principles related to their health, suggesting that community leaders could play an educative role in their communities using religion to influence change.
- There was some recognition of various cultural factors and discussion about how they influenced health.
- The cultural practice of living with extended family emerged as an interesting finding due to its implications for managing diabetes.

Socio-economic status and discrimination

- Experience of discrimination was very uncommon but people's financial situations often influenced the extent to which they could maintain a healthy lifestyle.
- The cost of travel was a barrier to attending appointments, which sometimes resulted in people missing appointments altogether if they could not afford the bus or taxi fare.
- Managing diabetes by maintaining a healthy diet was sometimes difficult for people as they perceived healthier food to be more expensive.
- When people were a carer for a partner or relative, this often conflicted with the time they had available for attending health appointments, attending other services in the community, and maintaining a healthy lifestyle.

Sources of support

- The doctor was perceived by many people as best placed to assist them with their long-term health condition.
- The Diabetes Specialist Nurse played a significant role in the management of diabetes, giving people time and providing emotional support.
- Resources within communities, such as local community organisations, provided a valuable source of support based on cultural norms and values, familiarity, and trust.
- Family members played a significant role in providing practical help to their relatives in areas such as household chores, transport, interpretation and translation.
- There was a lack of awareness about self-help groups, with only a few participants having accessed them. However, they liked the idea of self-help and expressed interest in attending in the future.

Cultural competency

- People were mainly satisfied with health professionals' understanding of language, religious and cultural needs, although some expressed concerns that there was often only basic understanding of these needs.
- Some health professionals had a limited understanding of the diets of different communities when providing advice, which limited the impact of their recommendations.
- The diabetes educational programme – Juggle – was cited as an example of good practice for its cultural sensitivity in providing bilingual trainers and educational content tailored to reflect the diets of different communities.
- The diversity of BAME groups in Nottingham City, which has expanded in recent years, is not necessarily reflected in the cultural awareness training that is provided.

Conclusions

What are the blocks and barriers to people from BAME communities with long-term conditions accessing and taking-up existing long-term conditions services?

The research has identified a number of factors associated with the uptake of long-term conditions services by people across Nottingham's BAME communities². These factors can be both *barriers to* and *enablers of* service uptake, depending on whether and how effectively they are addressed.

Language and communication

Poor English language skills were found to be a significant reason for the low uptake of services as these affected an individual's ability to communicate with health professionals about their condition(s) (and vice-versa). Where people had regular contact with health professionals who spoke their first language they were able to access services with greater ease. Although communication in a person's first language was always preferable good quality translation was found to be an effective alternative but, conversely, where translation was of a lower quality and consistency this was found to inhibit service use and understanding. Many people did not use translators, relying instead on family members to communicate with health professionals on their behalf and facilitate their engagement with services. When translators were not provided and family members were not available this could lead to insurmountable language barriers and a frustrating experience of engaging with health services that had negative consequences for people's management of their health condition.

Awareness and understanding of health conditions

There was a general lack of awareness and understanding about the symptoms and management of long-term conditions which held people back from accessing primary and community services. Often these gaps in knowledge originated from the diagnosis process but were exacerbated by an ongoing lack of information about their condition and the importance of managing its symptoms. When people did access educational support and/or specialist services they had much more confidence about how to manage their health condition.

Provision of services

The flexibility and accessibility of services was a key concern for people with long-term health conditions. Providing convenient appointment times and delivering services and educational programmes in accessible locations were key factors in their uptake. People were keen to attend health appointments and broader services but these were more likely to be taken up if they were within easy reach of their home and could be fitted around their daily work, family and wider commitments. Services were viewed more positively and considered most effective when there was continuity of staff and where they had been attentive to specific cultural and religious needs.

² These are a series of overarching factors that affect the range of BAME communities in the City of Nottingham. However, at a community level these need to be understood in the context of the specific cultural and religious norms of those communities such as language, diet, routines and practises.

Marketing and publicity

Information about the symptoms and management of long-term conditions was not typically offered to people in their first language and all correspondence relating to appointments, referrals and results was provided in English. This made such information inaccessible to people with poor English literacy but translated material could also be ineffective where people were illiterate in their first language as well, particularly when complex health information needed to be conveyed. Face-to-face contact with services, outreach workers and other native speakers with the same condition was a more effective and preferable way of learning about their condition for many people.

Sources of support

Although many people still viewed their GP or doctor as being best placed to support them with their health condition other important sources of support were also identified. ***Within health services*** this included specialist nurses, who tended to have more time to listen to people and provide emotional and practical support relating to their condition. ***Beyond health services*** this included family members, who played a significant role in providing emotional and practical help with the day-to-day effects of people's health conditions. It also included community resources, such as local community organisations, whose understanding of cultural norms and values created an environment of familiarity and trust where a broad range of help, advice and support could be accessed. Although there was a general lack of awareness of self-help groups, those who did participate in groups were positive about their impact, and many people not currently accessing self-help expressed an interest in getting involved in the future.

Overall, where people were confident and able to access support from a broader range of sources they were generally more effective at managing their condition independently.

Socioeconomic status and discrimination

Experience of discrimination was very uncommon but people's ability to maintain a healthy lifestyle was often affected by their financial situation. The cost of travel sometimes prevented them from attending health appointments and healthier food was often perceived to be more expensive. Where people had additional caring responsibilities this often limited the time they had available to attend health appointments, engage with wider services and maintain a healthy lifestyle.

Cultural awareness and competency of health professionals

People were generally happy with professionals' understanding of their language, religious and cultural needs but there were some specific examples where this could be improved. This included understanding the broader diets of different BAME communities and how these were shaped by religious practices and cultural norms, which limit the impact of dietary recommendations. The diabetes educational programme - Juggle - was cited as an example of good practice for its cultural sensitivity in providing bilingual trainers and content that was tailored to reflect the diets of different communities. However, more generally, the expanding diversity of BAME communities in the city is not necessarily reflected in the cultural awareness training that is currently provided to health professionals.

Recommendations from the research

How should the CCG, GP practices and service providers engage with BAME communities most effectively, including through an asset-based approach?

The research highlights the importance of co-production: involving people and communities in strategies and services that help them to manage and improve their health. People were most confident about managing their health condition when they were able to access effective support from health professionals in combination with support from family members, community organisations and/or self-help groups. As such, each of these different groups should be considered key stakeholders in the *engagement of* and *support for* people from BAME communities with health conditions.

The CCG's current strategy for developing local 'assets' to support and engage with people from BAME communities with health conditions and their families centres on growing self-help. Although there is evidence from the research that self-help groups are effective for the people who use them they are not being accessed very widely at the moment and there are a range of assets that could be utilised more fully. In particular, Nottingham City has a number of longstanding and trusted BAME community representative organisations with considerable *reach into* and *understanding of* the communities they serve. For many people in BAME communities these organisations are a first port of call for culturally sensitive advice, help and support and they are ideally positioned to play a central role in the engagement of BAME communities in co-produced approaches to support long-term health conditions moving forward.

What changes need to be made to the way services are delivered?

The findings suggest that Nottingham City CCG, with the support of its local statutory partners, have made considerable recent progress in transforming the way people from BAME communities are supported to manage long-term health conditions, in particular diabetes. As such, wholesale changes to the way services are delivered are not required. Rather, we make a number of recommendations about how this progress can be built upon and learning transferred to other service areas, such as respiratory conditions, alongside some specific recommendations for consideration in a number of areas.

Broadening self-help and utilising a wider range of community assets

The CCG has made good progress developing and implementing asset-based approaches in recent years, in particular through its work with Self-Help Nottingham, but there is potential to broaden the reach and coverage of self-help yet further and raise awareness of self-help opportunities and their benefits. Self-help is most effective when groups reflect the cultural knowledge of the communities that they are targeted at, and run in the heart of local communities to ensure accessibility.

In addition, the CCG could make more effective use of the many BAME community organisations in Nottingham City to engage with harder to reach or seldom heard individuals in these communities and support them with their health needs. However, many of these organisations are very small and operate with limited funds, so any plans to utilise them more widely should be incorporated within wider commissioning and engagement strategies to ensure that their involvement is appropriately resourced.

Increasing the diversity and improving the cultural competency of the workforce

The research identified the diversity and cultural competency of the workforce as a barrier that prevented some people from BAME communities engaging with health services effectively. The CCG should therefore consider a contracting approach with its providers that promotes workforce diversity for specific services so that the people delivering services are more representative of the communities they are required to support. Linked to this, people sometimes felt that staff lacked the cultural and religious knowledge and language skills necessary to engage with them effectively. As such, it is recommended that the CCG review with their providers policies around 'cultural competence' training, for although it is mandatory for many staff in health settings it is not updated on a regular basis. Doing so would ensure that cultural competency and awareness is embedded across primary and community services.

Improving awareness and accessibility of primary and community services

Awareness of primary and community long-term conditions services was generally low. Although most participants engaged with GPs, practice nurses and specialist services in support of their condition, many did not engage with the wider suite of services available to them and did not have sufficient information about how and where to access these services or why they would be beneficial. As such, the CCG should consider a strategy for raising awareness of services from the point at which a diagnosis is made that utilises a variety of channels that are appropriate for the BAME communities they need to target. Rather than written and visual materials, consideration should be given to raising awareness through community organisations and radio, outreach workers and religious leaders.

In addition, the research found that health services and information were often not sufficiently accessible to people and this could limit their ability to engage effectively. This included the language barriers associated with accessing and communicating with health services and health professionals, the formats in which information was communicated, and the physical location of services when people had to travel considerable distances to access them. Overall it was felt that health services would be more accessible if they were better tailored to patients' personal circumstances. As such, the CCG should consider how it can commission more accessible primary and community services in terms of **how** and **where** services are provided.

Monitor uptake of primary and community services

The CCG is committed to increasing the uptake of primary and community services by people from BAME communities with long-term health conditions. However, data on the ethnicity of service users is not collected routinely or consistently across these services. This limits the ability to analyse and review the uptake of these services generally, or of specific services by specific BAME groups. The CCG and its partners should therefore consider developing a consistent approach to monitoring the ethnicity of service users and regularly analysing uptake of services to identify overall progress and any patterns associated with changes in strategy or service delivery.

What are the next steps for commissioners to support a sustained increase in uptake of long-term conditions services by BAME communities?

As a first step, in response to this research, the CCG will need to consider the implications of the key findings and the extent to which the recommendations above should be taken forward. However, this report also provides an opportunity to reflect on the CCG's overall strategy around asset-based approaches to health and engagement, and the progress made towards embedding an asset-based approach to primary and community services for BAME communities. In the interim report we drew heavily on the work of Morgan (2014) and Hopkins and Rippon (2015) to identify a series of principles against which progress by CCG

and its statutory, voluntary and community sector partners towards implementing an asset-based approach to increasing the uptake of long-term conditions support in Nottingham City by BAME communities could be monitored and evaluated. Figure 1 (overleaf) draws on the key findings from the research to highlight progress against these principles to date and suggest a series of next steps towards greater implementation and integration of asset-based working.

Figure 1: Progress towards an asset-based approach to primary and community services for BAME communities in Nottingham City

	Underpinning principles	Progress made	Next steps
1 Prioritising	Prioritising approaches that emphasise building positive well-being and associated psychosocial resources.	The CCG has made asset-based approaches to working with BAME communities a strategic priority, as evidenced by its support for the development of self-help across the city.	A broader approach to asset-based working could be developed. This might involve expanding self-help provision across the city as well as involving a wider range of community level organisations in commissioned service delivery.
2 Involving	Involving individuals and local communities effectively and appropriately, for example by embedding the principles of co-production.	The CCG has proactively engaged BAME service users and community organisations in the development of recent commissioning strategies.	To continue engaging service users and community organisations in service development, ensuring the broadest possible representation of BAME communities and organisations, including from the hardest to reach and seldom heard groups.
3 Connecting	Connecting the individual with community and broader society, including through solutions and activities that utilise and develop voluntary organisations and community groups.	Through their work with Self-Help Nottingham the CCG is investing in a wide range of peer-led self-help groups for people from BAME communities across the city.	The CCG should promote as widely as possible referral from health services into the wider voluntary and community sector, building on its existing work on social prescribing.
4 Integrating	Working in a decision-focused, multi-professional and multidisciplinary way, including through integration of teams working in health, social care and community development.	Although the research did not explore integrated multi-disciplinary working we understand this has been a feature of primary and community care across the City since 2013.	To review the effectiveness of current integrated multi-agency approaches in the context of the <i>barriers to</i> and <i>enablers of</i> service uptake identified through this research.
5 Investing	Securing investment from a variety of sources (statutory and non-statutory) through a multi-method, evidence-based approach.	Current investment in asset-based working, such as the CCG's partnership with Self-Help Nottingham, draws solely on mainstream CCG budgets. Furthermore, the impact of asset-based working on service uptake by BAME communities is unknown.	The CCG should aim to broker the broadening of statutory investment in asset-based working to include, for example, Public Health and Adult Social Care, as part of city-wide multi-agency strategy for asset-based approaches. The impact of self-help on service uptake should be robustly evaluated.