Piloting the first participatory budgeting exercise in the NHS using the techniques of community organising to shape the future of health and care in Newham

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CONTENTS **PAGE**

1. Abstract

Using community conversations to address health issues is consistent with recent work on the 'asset based' model of health improvement, and 'empowerment based' initiatives (Domiguez and Arford, 2010; Durie and Wyatt, 2013).

The East London Citizens Organisation (TELCO) welcomed the invitation to work with Newham Clinical Commissioning Group, building on 23 years of working with Newham Residents bringing about change through successful campaigns for the Living Wage, Affordable Housing and Jobs. With 85 multi-faith, multi-cultural member institutions in membership we reach over 100,000 people across East London.

This report describes the process of community engagement and provides an overview of participants involved in the Participatory Budgeting project undertaken by TELCO on behalf of Newham Clinical Commissioning Group.

Between September 2018 and February 2019, 90 representatives from civil society institutions attended house meetings. Following the House Meetings, a meeting is scheduled with the Lay Member for Patient and Public Engagement, and the Mental Health and Children' and Maternity Commissioners for 26th February 2019, and presentation to the Clinical Commissioning Group Board will be on 25th April 2019.

We look at the role of anchor institutions and local leadership and highlight the challenges and potential of community organising in shaping the commissioning process for health services.

Broad themes from community conversations with residents are presented in this report, as well as priority issues identified by residents through six community conversations. Priority issues will be presented for consideration by the CCG Board for the 2019/2020 budget.

Finally, the report sets out opportunities for partnership working between Newham CCG and TELCO.

1. Prioritising the issues

The broad themes in the House Meetings Summary document (Appendix 1), highlight broad "Problems" within health in Newham, with some examples of how they are currently experienced. It was agreed to narrow down the list of problems to specific and manageable priority issues which lead to action and solution, otherwise the "problems" are too vast and unfocussed and will lead to inaction and apathy.

2. Priority issues for consideration by the CCG Board

- **Post-Traumatic Counselling services for refugee communities**
  Leaders from Shpresa Programme spoke of their work with refugee families and individuals living with the experience and trauma of fleeing from war and conflict in Albania, and how this often leads to other issues such domestic violence and young people joining gangs in their community. Shpresa Programme are also connected to other refugee and migrant groups from Somalia and Syria who experience the same issues.

  Participants see the need for a commissioned service of post-traumatic stress counselling

- **Loneliness**
  Participants raised Loneliness as an issue of concern identified across faith based and civil communities in Newham. Loneliness was seen as predominantly affecting elderly people. Participants shared experience and discussed the impact of 'worried well' using GP's as a way of alleviating loneliness.

  Depression and loneliness were also raised as issues affecting young children. Participants highlighted the need for early intervention and coping mechanisms.

  Participants explored how current models of reducing loneliness involving sign-posting to services, and activities including volunteering could be more effectively organised by the creation of GP register of Loneliness which would inform targeted referral and service provision and monitoring. They also felt that community organising would provide an effective model of community engagement, training and developing which could support the implementation of a loneliness register

- **Breast-feeding programme**
  Residents who run the Newham National Childhood Trust breastfeeding peer support programmes highlighted issues of funding, bureaucracy and ongoing support

  Since July 2017, the programme has built up a base of supporters providing women, mother-led, one-to-one and group support most days of the week, all year round in hospital and community settings. The programme has built excellent relationships with existing organisations and institutions, like Newham University Hospital, the Newham Health Visiting Team and Sure Start Children's Centres.

  However, the programme is currently self-funded, and the problem of support for new mothers still remains. There are many areas that require more support.

Local NCT branch finances have only been able to pay for training two groups so far. The programme has potential to grow.

The breast-feeding programme was raised as a priority issue requiring funding for a two-year pilot program of an NCT-run breastfeeding peer support program. This would entail:

- £8,000 p/a for training 24 peer supporters per year (2 teams of 12 each year), including insurance and reflective practice sessions
- £12,324 p/a to fund a part-time co-coordinators role for the two-year breastfeeding peer support program Employing a coordinator, or co coordinators for this project will enable the project to run smoothly, grow and expand its reach in the community.

- **Total for the two-year pilot: £40, 648 (£20,324 p/a)**

Potential for programme roll-out:

The pilot programme would collate data and test feasibility of a full roll-out similar to the £328k p/a Tower Hamlets borough-wide breastfeeding support program that run by Breast Feeding Network with the Royal London maternity services

Solutions for Breast Feeding programme included:

- Key leaders felt that current problems with getting volunteers onto the wards could be resolved relatively quickly by unblocking the bureaucratic processes which were perceived to be hindering progress.
- Bart's Health Volunteer Team to draw up a document or flow chart with exact specifics of each step that a Breastfeeding Champion volunteer needs to take in order to volunteer at NUH.
- Document/flowchart to have an approximate timeframe for each step
- Document with the contact details for each Bart's Health Volunteer Team employee to correlate with each step of the induction. If volunteers have an enquiry about the step, they need to know who to contact.
- When volunteers' names are first emailed to Nancy, could they please be sent this information as well as given the information for upcoming training dates.

Methodology

Key leaders discussed four priority issues for consideration by the CCG Board. Criteria for selection was based on community organising methodology for 'cutting an issue':

- Winnability–is this is SMART issue?
- Worthwhile – Is the issue deeply felt and worth spending time and money on?
- Impact –Is the issue widely felt and will change make a real difference in people's lives?
- Budget – will the issue involve spending or saving money?
- Clarity – will it be easy to understand
- Power - Is this an issue which would give people a sense of their power?
- Consensus – Will it unite our membership?
- Relevant – Is it something the CCG have the power to change?
- Legacy – Will the issue set our organisation up for the next campaign?

The above criteria provided a framework for agreeing the priority issues. For example, the issue of unacceptable attitude of receptionists in GP practices was raised as a widely-felt issue which should be included in the report, however this was not considered a priority in the context of participatory budgeting exercise and the other issues under consideration. However, while the Newham CCG Primary Care Commissioning Team have developed an education programme to improve customer service skills of all practice staff, it is not clear to what extent the CCG involve service-users in evaluating improvements.

2. Community organising as a vehicle for community conversation

Community organising starts from the premise that:

- Problems facing inner-city communities do not result from a lack of effective solutions but from a lack of power to implement those solutions;
- The only way for communities to build long-term power is by organising people and money around a common vision; and
- A viable organisation can only be achieved if a broadly-based indigenous leadership – and not one or two charismatic leaders – can knit together the diverse interests of their local institutions [1]

Professional Community Organisers and local leaders trained in the methods of community organising facilitated six 'house meetings' attended by over 80 residents belonging, or connected to, a civil society institution in their locality.

A house meeting is a small gathering of between eight to twenty people who are invited by a trained community leader they know and trust to discuss issues of shared concern and develop ways to work together. The comfortable and familiar setting is an ideal forum to

[1] Ivereigh, Faithful Citizens, 2010 p32

get to know people, share information about an organization and its issue campaigns, listen to what people have to say, and encourage guests to get involved.[2] Meetings do not always have to take place in someone's home, and can be hosted by a civil society institution that people belong to, such as a church, mosque, school or community centre.

Participants shared their experiences of health in Newham and answered the following questions:

- Question 1: What is working well
- Question 2: What is not working well
- Question 3: What is missing

3. House Meetings: Participant Numbers and Locations

House meetings took place at:

1. St Bartholomew's Church and Community Centre, East Ham
2. Shpresa Programme, Plaistow (Albanian community organisation), Plaistow
3. Bryant Street Methodist Church and Community Centre, Stratford
4. St Stephen's Roman Catholic Church, Manor Park
5. Caritas Anchor House, Canning Town.

Ethnicities represented in the meetings were White British and White Irish (35%), Black African and Black Caribbean (45%), Eastern European (20%).

Participants included residents in a homeless shelter; migrants who might be considered hard-to-reach, and of whom 30-40% had English as their second language; long-term residents; residents who are actively involved in promoting health in the borough as volunteers, and pensioners who have lived or worked in Newham for more than 10 years.

Participant gender split was 60% female and 40% male and ages ranged from 11 to 70 years old.

4. Key Findings

Broad themes[3] emerging from Question 1 and 2 were:

1. Quality of care
2. Responsiveness
3. Patient voice and experience
4. Administration and bureaucracy

[2] http://www.worc.org/media/Hold-a-House-Meeting.pdf
[3] See Appendix 1

5. GP services
6. Referral services
7. Money and affordability

Additional themes under 'other' include: prevention and self-care; information that is easy to understand; relationship between patients and GPs; local authority and civil society groups; relationships between patients and locums; and provision of health services for homeless people.

Responses to Question 3 were captured under 'NHS and Community' and highlighted perceived gaps in health provision including:

- Wellbeing provision and preventive work in mental health:
- Community health
- Tackling Loneliness in elderly people and Depression in young children

5. The uniqueness of community organising methodology

Essentially, Community Organising is about returning power to people. It prioritises personal relationships, membership of institutions rooted within the community and a pragmatic approach to influencing people who hold power in government, business or public life.[4]The model of broad-based community organising used by TELCO is often called 'institutional organising' due to the focus on organisational membership rather than individual membership.

The role of anchor Institutions

The process for engagement was informed by community organising practice which places emphasis on identifying 'anchor institutions' as places with organised people and organised money.

"An anchor institution is one that, alongside its main function, plays a significant and recognised role in a locality by making a strategic contribution to the local economy. Anchor institutions are characterised by:

- **Spatial immobility:** these organisations have strong ties to the geographic area in which they are based through invested capital, mission and relationship to customers and employees

[4]https://www.citizensuk.org/tags/community_organising

- **Size:** anchor institutions tend to be large employers and have significant purchasing power. Both these factors influence the level of impact these institutions can have on the local economy

- **Non-profit**: these institutions tend to operate not-for-profit; it is much simpler for private businesses to move, meaning there is no guarantee they will continue serving the local community in the long-term. However, there are examples of for-profit organisations playing the role of an anchor."[5]

For the purposes of the Participatory Budgeting exercise, anchor institutions were identified on the basis of their deep roots and their role in social impact in their locality. Institutions were members of the local Newham Citizens alliance or allies with similar values and mission in enabling people to participate in public life.

The role of local leadership

Identifying 'key informants' may be pivotal in achieving maximum benefit from such community-based initiatives (Kesten et al, 2015). There are also examples where 'coalitions' of various community groups, universities and health departments have led to health improvements, such as a reduction in obesity in communities where obesity and associated poor health outcomes have been an issue (Liao et al, 2016).

The concept of local leaders acting as 'key informants' is at the heart of citizen organising methodology which is deeply respectful of local knowledge and experience. The social capital within our member institutions can be understood as pockets of relational power: community organising depends upon harnessing this.

In our experience, the engagement of social networks of 'hard to reach' communities depends on local or indigenous leaders. These are the real representatives of people in the community and it is they who have the ability to inspire people's belief that they can realise their goal. Local community leaders are ordinary citizens who have deep relational roots in the community. They are supported and trained by professional Community Organisers to galvanise the social capital within their institutions and to build stronger bonds, reciprocity and solidarity. From this basis they create links to outside agencies and to the assets of those external organisations able to provide access to services.

In community organising, a leader is defined as 'anyone capable of delivering a following consistently.' There are three tiers of leadership in organising methodology:

[5] https://ukces.blog.gov.uk/2015/03/19/ukces-explains-what-is-an-anchor-institution/

1. Tertiary leaders are members of organisations whose following is their family, friends, neighbours, or work associates;
2. Secondary leaders are influential members or positional leaders who are more involved in meeting the needs of their institution;
3. Primary leaders are experienced leaders and decision-makers within their institutions but are also committed to build the wider alliance

For the project, primary and secondary leaders used their existing networks to engage tertiary leaders to attend community conversations. Six leaders were selected from our Newham Citizens alliance based on:

- Access to a community network
- Previous experience of developing and mobilising their following
- Personal interest in issues on health
- Location of their institution within the borough
- Type of institution or group

Consideration was given to the above criteria for selection to ensure:

- Active participation and local ownership
- Involvement of people affected by issues of health in a process which has potential to bring about real improvement in their lives
- Engagement with existing social networks, and where possible match this with known areas of health inequality such as Manor Park
- Diversity of participants

6. Conclusion

The Participatory Budgeting exercise has highlighted the role community organising can play in tackling health inequality in Newham. In light of the changing demography in Newham, there is a real threat of health inequality concentrating in areas which already face serious health inequalities. There is a need to ensure that health services are responsive to the needs of the most vulnerable and hard-to-reach people in the borough. TELCO, other organised civil society group and Newham CCG have an opportunity for real and meaningful engagement and partnership to create health services which are fit for purpose for all in Newham (See Appendix 2)

7. Acknowledgements

- Newham Clinical Commissioning Group
- Birkbeck University of London
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- St Stephen's Roman Catholic Church, Manor Park
- Caritas Anchor House, Canning Town