Camden Health and Care Citizens' Assembly

Overview of the session
27 July 2020

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CAMDEN HEALTH
AND CARE CITIZENS'
ASSEMBLY

Contents

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Reminder of Assembly process

Event 1 Feb 2020 (face-to-face)	Event 2 June 2020 (online)	Event 3 July 2020 (online)	Event 4 Sept 2020 (online)	Event 5 Planned for Sept 2020 (TBC based on Covid19 regulations)
Introduction to the Assembly and identified priority areas to discuss and focus on as an Assembly.	Regrouped after the pause due to coronavirus and shared experiences of the pandemic. Also reminded ourselves of the priority areas.	Having a more in-depth discussion about your **priority area 1 'reduce health inequalities'** and what you would like to change.	Having a more in-depth discussion about your other **priority area 2 'staying healthy safe and well'** and what you would like to change.	Determining the expectations that you have of the Council and partners in addressing the priority areas you identified. We will draw together all the comments and insights shared from the previous sessions and from your citizen scientist work.

We are **here** in the process

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Section 1: Why are we here?

On 27 July 2020, we brought together the Camden Health and Care Citizens' Assembly for the **third assembly session**

During the session, we covered:

1. Welcome and introductions
2. What we learnt from the last session
3. Learning more about health inequalities
4. Discovering our expectations
5. Next steps

This pack provides an overview of our discussions

Objectives for the session

- Remind ourselves what happened in the last meeting
- Understand 'health inequalities' in Camden
- Discuss some of your expectations about health inequalities in Camden
- Instructions for between now and next meeting

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We began the discussion by reminding ourselves what we learnt and discussed at the last assembly meeting

What we covered...

- We regrouped as an assembly
- We were reminded of our objectives
- **You shared your experiences of the COVID-19 pandemic**
- We revisited the priority areas and assessed how they should change
- You were provided instructions for next steps

Key challenges for you and your community during the pandemic

- Feeling isolated / alienated from others
- Financial difficulties
- Worrying about friends and family members (particularly older relatives)
- Parenting during lockdown
- Accessing health services
- Impact on disabled people and those with health conditions
- Accessing the right information and relying on digital
- Overarching impact of COVID-19 on mental health

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Adjusting our priority areas

As things had changed a lot since the last meeting, you were shown some suggested adapted versions of the **three priority areas** which take into account the new Covid-19 context.

You gave your feedback on those adjusted priority areas, pointing out what you liked and didn't like about them.

We took all of your feedback into account, and have settled on a final version...

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We began the discussion by reminding ourselves what we learnt and discussed at the last assembly meeting

Priority 1
Reduce health inequalities in the borough. Ensure that local services can tackle the impact of the pandemic on the most affected groups.

Priority 2
Ensure my family, friends, neighbours and I can stay healthy, safe, and well in Camden, particularly our mental health and emotional wellbeing.

Priority 3
Ensure local services work together to meet the needs of residents, and communicate effectively with residents.

In this session, we focused on Priority 1:

We aimed to gain a better understanding of what 'health inequalities' mean and explore what participants want to change in Camden.

The ideas shared in the session will help us to, in our final session, set some principles for Camden Council to consider when addressing health inequalities in the borough.

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Before discussing our expectations and what we'd like to see changing in Camden, we explored what we meant by **health inequalities.**

What are health inequalities?
Health inequalities are avoidable, unfair and systematic differences in health between different groups of people.

They are differences between different groups in:

- Health status, e.g. life expectancy and prevalence of health conditions

- Access to care, e.g. availability of treatments

- Quality and experience of care, e.g. levels of patient satisfaction

- Behavioural risks to health, e.g. smoking rates

- Wider determinants of health, e.g. quality of housing

Find out more about health inequalities here:
www.kingsfund.org.uk/publications/what-are-health-inequalities

What you've already said about health inequalities as an assembly:

It's really important that the health services in Camden are supported and people born with disability are treated fairly and compassionately

Staff within the NHS need more training to be deaf aware

You need to be assertive and persistent to access what services are there. This means that more vulnerable people are at a disadvantage from the outset as they're more likely to walk away

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We shared what the assembly has already told us about health inequalities over the previous sessions

What you told us we should prioritise from session 1:

We should prioritise caring equally for all sections of the community of the Borough of Camden, with humanity, social justice, dignity and respect, improving quality of life for every single human being

We should prioritise effective support for inclusion and accommodation of every resident

We should prioritise catering for Black, Asian and Minority Ethnic section of the population. Also for LGBTQ+ members of the public. 'Inclusion of all' is also on the senior board members making the decisions!

We should prioritise supporting the 'hard to reach' group of residents

Challenges of Covid-19 you told us about in session 2:

There are difficulties for disabled people to get support and receive information. You suggested a line of support for disabled people to support access services

For isolated people not able to use digital technology, it was difficult to receive and access information and get mental health support

As a wheelchair user and single mother, Covid-19 presented an extremely challenging and scary situation... There are a lot of disabled people in the same situation... The difficulties of infection avoidance and control are multiplied for disabled people

My parents have really struggled... There have been lots of letters, but we can only provide help over the phone, so can't physically see the letters

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We then focused on learning more about the realities of health inequalities in Camden.

We began by hearing from **Matthew Parris, Director Healthwatch Camden.**

Matthew shared insights from research in the community about people's experiences during Covid-19 to illustrate how health inequalities play out in people's lives in Camden.

In particular, Matthew shared:

Matthew Parris
Director,
Healthwatch Camden

- **Concerns raised by Carers**

- **Heightened stress and anxiety among Black and Asian Minority Ethnic respondents**

- **Additional support needs of Parents of children with SEND**

"My Dad has Alzheimer's and my mum mental health issues and both are struggling without support groups and visitors and the situation is deteriorating as a result… they can't use technology very well for remote services."

"Not only are we dealing with feeding our kids, home schooling, working, and keeping safe, now we also have to explain this [increased risk for BAME communities] to our kids who hear things on the news and they are scared."

"My son used to have physiotherapy. Now I do all the manual handling. He's in a wheelchair. He has a hoist but all of the changing and bath I do on my own. I'm exhausted."

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We then heard four short talks from local organisations working to tackle health inequalities in Camden.

We asked each speaker to answer the following questions:

1. What was life like for the population group you serve before Covid-19?

2. How has the pandemic changed how people receive local health and care support?

3. What could change to reduce the impact and help this group more in the future?

Tessa Havers-Strong

forum⁺

Benaifer Bhandari

Hopscotch
Asian Women's Centre

Annabel Collins

Camden age UK

Brendan Leahy

CAMDEN DISABILITY ACTION

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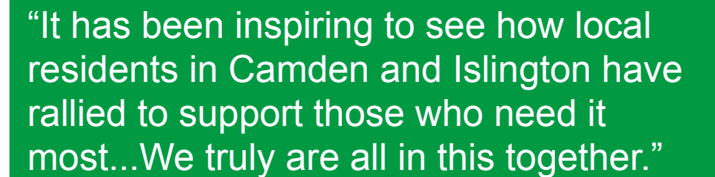CAMDEN HEALTH AND CARE CITIZENS' ASSEMBLY

We then heard four short talks from local organisation working to tackle health inequalities in Camden.

1. **Tessa Havers-Strong - Forum+**

Forum+ works to promote equality for LGBTQ+ people in Camden & Islington.

Tessa highlighted:

- At the start of the pandemic, the main concerns coming to Forum+ were about access to health care, continuation of prescriptions for long term health conditions, like HIV medications and worries about being able to buy food and essential supplies. The intervention of the councils and local organisations in supporting those who had to stay at home was crucial.

- A recent survey on how the pandemic impacted LGBTQ+ lives showed that 80% of those who responded said their emotions had been negatively affected and 42% felt some form of significant isolation.

- In particular, what would help is:
    - Improved communication by statutory bodies to service users
    - Better access to GP services via online digital technologies
    - Better access to mental health support services

"It has been inspiring to see how local residents in Camden and Islington have rallied to support those who need it most...We truly are all in this together."

Tessa Havers-Strong

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We then heard four short talks from local organisation working to tackle health inequalities in Camden.

2.   Benaifer Bhandari - Hopscotch

Hopscotch's mission is to enable Asian women to actively participate in society and make informed decisions that enable them to achieve their aspirations.

Benaifer highlighted:

- Some of the barriers that already existed for their community, including language barriers, location and cultural taboos.

- They found that a slow government response led to confusion and that there have been higher levels of isolation, beyond government guidance. There have been issues with accessing clear and trustworthy information.

- In particular, what would help is:

  - Clear information and guidance from the beginning for service users and for community organisations who support service users.

  - All information available in community languages, and having community members and interpreters available. More appropriate pictorial response relevant to extended families living in smaller homes.

  - Quicker response rate from government to support community charities and continuing to keep community organisations involved in decision making

We then heard four short talks from local organisation working to tackle health inequalities in Camden.

3. Annabel Collins - Ageing Better in Camden

Ageing Better in Camden is a programme within Age UK Camden that funds organisations to find socially isolated and lonely older people and connect them to activities which they fund across the borough.

Annabel shared:

- Covid-19 highlighted the inequalities that existed within older people, particularly around poverty and racial inequality.

- When lockdown started, a significant number of older people were told not to go out, and some had no access to food or family who could organise it for them. For those with strong connections to local community centres or organisations they had a trusted organisation to call who could help them get on the food parcels list. For those who didn't this was a time of huge anxiety.

- The digital divide was highlighted. In 2018 Ofcom data showed that almost half of those aged 75 and over are not using the internet. During lockdown being online became such an important aspect of both practical and emotional connection – from buying food and, seeing your doctor to chatting with friends.

- In particular, what would help is continued focus on isolated older people, funding and support for older people who want to be online, and ensuring non-online support remains embedded within all services.

"Older people are not only vulnerable, but valuable assets in their communities. They are the helpers as well as the helped. And it is essential that their voices are included in these conversations around experience and recovery."

Annabel Collins

We then heard four short talks from local organisation working to tackle health inequalities in Camden.

4.   Brendan Leahy - Camden Disability Action

Camden Disability Action is a pan disability Social Change Charity in Camden.

Brendan shared:

- Accessibility of services is a main barrier and is impacted by proper communication from the health and social care professional in the community.

- GP's and Hospitals have been an extremely challenging and inaccessible place before Covid-19 and during the pandemic they have become even more challenging, because they have been closed or have restricted their access. Where they are still available, some people with a Learning Disability have been scared or frightened to contact services, as they either don't know how to, don't have the technology, are worried they will catch the virus in a medical setting, or don't understand they are unwell and won't reach out to the medical professionals.

- Some families have been excluded from seeing their loved ones that they do not live with, and for them and that has been a challenging place.

- Many disabled people are also BAME, LGBTQ+, and/ or older, for example, and so they also experience many of the inequalities discussed by Forum+, Hopscotch and Aging Better.

- In particular, what would help is training that is created and delivered in a joined-up way by people with a Learning Disability.

After hearing more about the context of health inequalities locally, and how organisations are supporting those most affected by the pandemic, we split into small groups to discuss what we'd heard.

In small groups, we discussed the following questions:

"Thinking about your 'ideal world', what unfair differences would you expect to be reduced?

Do you have any ideas about *how* to reduce them?"

<u>Why</u> did we do this exercise?

1. The discussions will help us understand what you expect from Camden in terms of tackling health inequalities.

2. We will revisit the ideas in the final session to form a prioritised set of 'expectations', which will be used to inform changes to health and social care in Camden.

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We asked **"Thinking about your 'ideal world', what unfair differences would you expect to be reduced? Do you have any ideas about how to reduce them?"**

Improving access to GP services

- Many residents discussed the difficulties in accessing GP services, with it being unclear whether services are open or how to access them.

- There have been confusing messages about how and whether to contact GP services, and it has made getting prescriptions difficult. **"The whole thing about how to access GP has been confusing; they didn't say they were closing. I've been able to renew my prescription by using an app."**

- There are challenges in making services online, as not everyone can access online consultations tools like Zoom, **"It's a battle to get through reception. And now services are online – that is a struggle."**

Better communication about how services work

- Some assembly members discussed how there needs to be a better understanding of how the health and care system and services work and a better method of keeping residents informed.

- Having information available in a range of formats is essential for keeping residents informed and for people with health conditions to know how to look after their own health better, and how to access services.

- **"We need to understand how health and care services are funded, options and consider paying for some parts of it out of our own pockets."**

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We asked **"Thinking about your 'ideal world', what unfair differences would you expect to be reduced? Do you have any ideas about how to reduce them?"**

Involving people in the design of services

- Some assembly members felt it was important to engage directly with communities to find out their views about services.

- In particular, speaking to service users, health and care staff and assembly participants to discuss the detail and decide on immediate and long-term actions.

- **"All of the equality groups need to be engaged in a conversation about the actions – service users, Citizens' Assembly participants, health and care staff."**

An easier way to navigate the system

- Some residents discussed how health and care systems can be confusing, and that you need to know how to navigate the system and be proactive to get through it. Those who can't navigate the system have poorer outcomes, which can make health inequalities worse.

- **"I feel that sometimes I have to be a bit pushy with accessing health services because they aren't very well joined up. Having to navigate this during Covid-19 is really difficult."**

- **"If you are good communicator with good digital skills etc., then you are in for a much easier ride – whether it is language or technical issues, etc, health inequalities are exacerbated by the fact that some groups do not know how to navigate the systems and therefore have fears of them, and some groups do."**

We asked **"Thinking about your 'ideal world', what unfair differences would you expect to be reduced? Do you have any ideas about how to reduce them?"**

Supporting community to use technology and digital solutions

- Some groups highlighted issues with people not having digital devices or not knowing how to use them, which led to isolation and for example, difficulties in finding information, keeping in contact with friends and family, and ordering shopping.

- Some felt there should be support for people to learn to use technology, and advice for where to access and acquire the right technology.

Having alternatives to online services

- In addition to making digital services more accessible, some assembly members felt that an online only offer is problematic, especially for those with anxiety issues, older people and those whose first language is not English.

- Telephone services (available in different languages) were highlighted as important, as well as walk-in facilities.

- **"Suffering from anxiety makes it more difficult to access services digitally as it can be cumbersome and you may not get someone to talk to answer your questions and you just give up... You may not have the equipment or connection."**

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We asked **"Thinking about your 'ideal world', what unfair differences would you expect to be reduced? Do you have any ideas about how to reduce them?"**

Services working together better to identify and understand community

- Some assembly members discussed how services like the Council and the NHS should work together and have more interaction to identify residents who are vulnerable, and to give them priority in terms of accessing GPs, support and care. Some members felt this approach worked well for residents with learning disabilities.
- Some members discussed the idea of developing a clear vision for working in partnership to support residents.

Support for local charity/voluntary organisations and groups

- Some groups discussed the importance of making sure that local organisations are able to support the community, especially as they have connections to vulnerable people and can provide outreach to the community are not coming forward to use services.
- Sufficient funding and resourcing of local organisations are important, and keeping them informed of relevant information.
- In particular, accessible 'drop-in centres' and 'coffee centres' were highlighted as potential services to offer support to the community.

We will revisit the expectations you have highlighted in our final session, where we will refine and prioritise the key points.

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Section 5: Next steps - your role as a Citizen Scientist

Finally, we discussed next steps, and shared the next task as Citizen Scientists.

Between events 2 and 3	Citizen Scientist Part 2:	Ask people in Camden about their experiences. It might be a family member, neighbour, postal worker, refuse collector, a delivery driver and/or your work colleague. You decide whom you want to ask.

Over the next few weeks, you can ask people in Camden about their experience since the Covid-19 pandemic began. Here are the kind of questions you might want them to answer, but don't feel limited by them:

- How did you feel when we were all asked to stay at home?
- Did you have to self isolate?
- Did you have to shield?
- Did you take regular exercise?
- Did you go food shopping or have it delivered?

- Did you miss your family, friends and neighbours? Who and what were you missing the most? Why?
- Did you volunteer to help others in the community? What did you do? Did you help a neighbour(s)?
- Did you join a WhatsApp group or phone tree?
- If you work were you able to work from home or did you still go to work?
- Did you learn a new hobby or learn a new skill?

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Section 5: Next steps - your role as a Citizen Scientist

- **Everyone has a different experience of COVID-19.** We want you to share something about the experience of people around you. For some it might be sharing something that was difficult or challenging, for others it might be positive things.

- **Please only share what your interviewees feel comfortable sharing with us.** No one has to share if they don't want to.

- **Anything that you do share will be anonymised.** This means that people seeing it will not know who it is from or about.

- **Please send your contribution** to HealthandCareCitizenAssembly@camden.gov.uk by **Wednesday 19th August.**

- **If you do not have an email address,** just phone us: **020 7974 1459.**

- **We can help you to do this task,** just let us know by email or phone if you need help.

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Thank you.

Thank you for such a constructive input to the session - we really appreciate it.

We look forward to seeing you at the next digital session, taking place:

● Tuesday 1st September 12-1:30pm

Please email HealthandCareCitizenAssembly@camden.gov.uk or phone 020 7974 1459 for any questions you might have.

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