



INTERIM REPORT

Co-designing a self-management and care programme in Islington

14 Feb 2020

INTRODUCTION

Islington Community Research and Support Programme

Over the last four years, Islington Clinical Commissioning Group (CCG) has worked with local community organisations to deliver the Community Research and Support Programme in Islington. The aim of this programme is to act on the CCG's commitment to engage with different communities in Islington, in particular those that face barriers to accessing statutory services and support. The CCG want to understand people's experiences, and gather their views on what impacts their health and wellbeing so that they can feed these views into their service design, commissioning programmes and strategic planning.

Self-care and self-management programmes in Islington

Some of the feedback the CCG received from the previous Community Research and Support Programme was about the self-care and self-management programmes currently offered to people living with long-term conditions in Islington. The feedback told them that there are good programmes that work well for many individuals. However, it also told them that sometimes the lack of flexibility in the programmes and activities can mean that those who experience the most barriers to accessing support and services are unable to take part.

Improving self-care and self-management in Islington

The CCG want to improve the health and wellbeing of all of Islington residents and patients. Based on the feedback they have received, they want to widen their self-care offer in Islington and increase the number of people living with long-term conditions who participate in these activities.

The CCG want to:

- Understand the barriers to accessing the support currently available
- Work with patients to find solutions as to how we overcome these barriers.

In particular, the CCG want everyone who could benefit from taking part in a self-care or self-management programme to have the opportunity to do so.

Co-designing a new programme of care in Islington

The CCG have commissioned Positively UK, working in partnership with Living Well, to work with people living with long-term conditions to co-design a more flexible programme of self-management and care in Islington.

To do this the following approaches to co-design will be used with both service users and professionals/tutors:

- Online Surveys
- One-to-one Interviews
- Focus Groups

Findings and recommendations will be shared in a full report at the end of March 2020. However, in the meantime, this document summarises current progress, shares data collected, presents interim findings and outlines next steps.

ABOUT LONG-TERM CONDITIONS

A long-term condition can be defined as any condition that cannot at present be cured; but can be controlled by medication and therapies.

Long-term conditions are one of the biggest issues facing health and care today. About 26 million people in England have at least one long-term condition. With 10 million reporting two or more conditions. Fifteen percent of people aged 11-15 have a long-term condition and only 59% of all people of working age living with long-term conditions are in work, compared with 72% of the general population.

Long-term conditions account for:

- 50% of all GP appointments
- 64% of all hospital outpatient appointments
- 70% of all hospital bed days
- 70% of health and care spend
- 50% of emergency bed days for over 75s
- 25% of bed days occupied by someone dying

Carers are making a huge and valuable contribution to looking after people living with long-term conditions but the burden on them is great. Eighty percent of carers report that caring for someone living with a long-term condition has had a negative impact on their health.

Currently, only 64% of people living with a long-term condition say they feel supported, meaning that over a third of them do not feel supported. So there is clearly room for improvement and much work to be done to ensure people living with long-term conditions feel supported and are empowered to maintain a good quality of life.

CURRENT PROGRESS

Outreach and Engagement

In October, November and December the project coordinator reached out to GPs and a wide range of local organisations that work with people living with long-term conditions. Meeting in person or over the phone with representatives from Help on Your Doorstep, Healthwatch Islington, The Whittington Hospital and The Village Practice. During these meetings, the coordinator raised awareness of the project, gathered intelligence and invited service users and professionals from those organisations to be involved in the project.

Online Surveys

Emails and surveys have been sent directly to over 50 people known to be living with long-term conditions in Islington, to 13 Islington GP Practices, and 19 local organisations including:

The emails raised awareness of the project and invited service users and professionals to become involved in the project by completing the relevant online survey and taking part in interviews and focus groups. So far 26 online surveys have been completed (18 by service users, 7 by healthcare professionals/programme tutors and 1 by a carer);

Interviews

Project coordinators have conducted 13 interviews with people that have responded to surveys saying they would be happy to expand on the responses that provided. With all of these people also invited to a focus group.

Focus Groups

Based on the data collected from the online surveys and interviews, we summarised the feedback received and shared that with five focus group participants to gather further comment and analysis.

In addition, we also created a number of Patient Personas – including name, age, sex, health condition, relationship status, family, lifestyle etc. - that focus group participants worked together to answer following questions such as:

- Who is your patient? What is their life like? What LTCs do they have? What challenges does your patient face?
- What barriers might prevent them from accessing existing care?
- What would the perfect self-care service look like for them?
- How would this service benefit your patient? How would it improve their life?
- How could we measure service impact?
- Anything else we need to consider when designing such a service?

This exercise enabled participants to come together to use their own experiences to evaluate the needs of others and start to co-design a new service model that might better support people living with long-term conditions in Islington.

INTERIM FINDINGS

Basic demographics of services users so far engaged:

- Age range: 21 – 80
- 70% male / 30 female
- 25% White European, 17% White British, 17% White Irish, 17% Black African, 8% Black British

Conditions people living with include:

- Cancer
- Angina
- Chronic respiratory diseases
- Chronic neuropathy
- Chronic pain
- Diabetes
- HIV
- Irritable bowel syndrome
- Mental health
- Kidney disease
- Chronic fatigues
- Osteoporosis
- Spinal stenosis

Self-management and self-care services people engaged have tried:

- DESMOND Programme
- Diabetes Self-Management Programme
- Long-term Exercise Programme
- Expert Patients Programme
- Help on Your Doorstep
- Recently Diagnosed Programme
- Pain Clinic
- iCope / Increased Access to Psychological Therapies (IAPT)
- Mental Health Programme
- Counselling / Talking Therapies
- Positively UK Over Fifties Programme

What people like about current long-term condition services in Islington:

- Topics broken into separate sessions
- Meeting others with the same condition who are doing well
- Receiving information
- Learning how to live well and enjoy life

What people don't like about current long-term condition services in Islington:

- Focus too generic
- Didn't deal with patient's specific issues
- Would prefer one-to-one help rather than groups (or at least a choice)

Barriers – what people feel prevents them from accessing current services:

- Lack of motivation
- Loneliness and Isolation – no one to speak to
- Lack of available appointments
- Chronic fatigue – struggle to get to support
- Mobility issues
- Lack of knowledge of what services exist Scared to ask for help – afraid to admit their condition, especially in a group, e.g. mental health issues
- Lack of confidence

What patients said a perfect service look like:

- Well publicised and promoted
- Accessible venues/times
- Facilitated by experts and expert peers
- Include an outdoor element, e.g. walks, exercise, cultural excursions etc.
- One stop drop-in shop providing holistic support
- One-off sessions – short/focussed - spaced throughout the year
- Groups bringing people with the same issues together
- Some form of online support
- A buddy support system
- Home support for housebound patients
- Evening and weekend sessions for those that work
- Learn new skills

Anything else people would like us to consider:

- Provide a mix of generic and condition-specific support
- Provide support to help people maintain their achievements
- Needs to be free
- Needs to feel like you are learning something new and making progress
- Needs to offer support / information they wouldn't get elsewhere
- People need to know the service exists
- Service needs to be delivered from convenient community venues

INTERIM CONCLUSION

There is currently a good range of effective one-to-one and group-based self-management and self-care support services available for people living with long-term conditions in Islington.

The main barriers to access seem to relate to service users:

- Lack of knowledge of what services exist
- Lack of understanding of what services would best suit their needs
- Lack of confidence and/or motivation to attend services
- Inability to attend – e.g. lack of mobility, inconvenient venue, unsuitable times

To help service users overcome these barriers and enable them to better engage with appropriate support services they need support from some kind of 'Long-Term Conditions Care Navigator' or 'Peer Link Worker' who would work with them on a one-to-one basis, over 1-6 sessions, to co-create a Care Plan to help them identify and prioritise their needs.

This Care Navigator/ Peer Link Worker would help the service user find the right support, at the right time and work with them to build confidence and/or motivation to engage with services. If appropriate, escorting them to their 1st appointments or making the relevant arrangements if disabled.

This Care Navigator/ Peer Link Worker would focus on the self-management of long-term conditions but could also have a more holistic focus of support, also helping service users with issues relating to finances and signposting them to a range of statutory and voluntary sector services.

PLANNED NEXT STEPS

Further analyse data collected from surveys, interviews and focus group to co-create a new model of care and support, with draft assessment tool, before sharing it with service users and healthcare professionals for further feedback and comment.

FEEDBACK FROM SERVICE USERS

In their own words: The following represents a sample of the feedback we have so far received from service users living with long-term conditions in Islington.

Respondent #1

Q1 What is your age? 54

Q2 What is your gender? Male

Q3 How would you describe your ethnicity? White Irish

Q4 What long-term conditions do you have and how many years have you been living with each?

- Diabetes 1-5 years;
- Encephalitis +5 years

Q5 Have you ever taken part in any self-care or self-management support services?

- Diabetes Education and Self-Management for Ongoing and Diagnosed (DESMOND);
- Diabetes Self-Management Programme;
- Expert Patients Programme (EPP)

Q6 If you have attended a self-care or self-management support service, what about it was beneficial and what could be improved? It gave me information to help with living and how I can learn to enjoy my life.

Q7 What do you think are the barriers that prevent people living with long-term conditions from attending self-care or self-management support services? And what could be done to better support them? Loneliness is a major factor. Feeling isolated. Not coping well on your own. Talking with other people helps ease this trauma.

Q8 If you were designing the perfect support service to help you live better with your long-term condition(s) what would it look like and how would it work? You need a venue that could facilitate a group of people and a teacher. Who can talk us through a program designed to meet our requirements. To have the facts presented; the myths put to rest and possible solutions to tried and tested dilemmas. Help encourage conversation and try to destigmatise. The initial course should maybe be 6 or 8 weeks long. Meeting once a week for 7 hours. With lunch and refreshments provided. Then there could be follow up courses of 3 or 4 days. To check in if you are on track. Dealing with your issues as best you can.

Q1 What is your age? 40

Q2 What is your gender? Male

Q3 How would you describe your ethnicity? White

Q4 What long-term conditions do you have and how many years have you been living with each?

- Chronic Respiratory +10 years;
- Irritable Bowel Syndrome +10 years;
- Mental disorder 1-5 years

Q5 Have you ever taken part in any self-care or self-management support services?

- Counselling/therapy

Q6 If you have attended a self-care or self-management support service, what about it was beneficial and what could be improved?

Access to therapy when I was heavily suicidal saved me. I struggled when the sessions finished but I understand there's a big requirement.

Q7 What do you think are the barriers that prevent people living with long-term conditions from attending self-care or self-management support services? And what could be done to better support them?

Scared to own up to being depressed, scared to ask for help. More awareness that the type of services I utilized are available and accessible fairly quickly.

Q8 If you were designing the perfect support service to help you live better with your long-term condition(s) what would it look like and how would it work? Venue - less harsh lighting - reminds me of the psych ward.

A support helpline or text service in addition to the therapy session where they have a record of your history and treatment would be helpful so you don't have to start from the beginning every time you call a service.

Q1 What is your age? 36

Q2 What is your gender? Male

Q3 How would you describe your ethnicity? White British

Q4 What long-term conditions do you have and how many years have you been living with each?

- HIV+10 years

Q5 Have you ever taken part in any self-care or self-management support services? Respondent skipped this question

Q6 If you have attended a self-care or self-management support service, what about it was beneficial and what could be improved?
Respondent skipped this question

Q7 What do you think are the barriers that prevent people living with long-term conditions from attending self-care or self-management support services? And what could be done to better support them?
Knowledge of the services available and how to access them easily.

Q8 If you were designing the perfect support service to help you live better with your long-term condition(s) what would it look like and how would it work? Evening sessions around 8pm to make it easy to get to after work and near a tube station to make it easy to attend. Something relaxed and friendly with people from a similar background. Also would be good to have the chance to learn new skills together and support each other in ways that could help outside the group.

Q1 What is your age? 45

Q2 What is your gender? Female

Q3 How would you describe your ethnicity? White

Q4 What long-term conditions do you have and how many years have you been living with each?

- Cancer 1-5 years;
- HIV+10 years

Q5 Have you ever taken part in any self-care or self-management support services?

- Recently Diagnosed Programme

Q6 If you have attended a self-care or self-management support service, what about it was beneficial and what could be improved?

Meeting other people with same condition who are thriving is very important at the beginning to understand how to cope with your diagnosis

Q7 What do you think are the barriers that prevent people living with long-term conditions from attending self-care or self-management support services? And what could be done to better support them? No information about the services. Info could be sent by post regarding services by your GP or hospital

Q8 If you were designing the perfect support service to help you live better with your long-term condition(s) what would it look like and how would it work? Massage and complimentary health services given in a non-hospital setting.

Q1 What is your age? 64

Q2 What is your gender? Male

Q3 How would you describe your ethnicity? White British

Q4 What long-term conditions do you have and how many years have you been living with each?

- Cancer+10 years;
- Chronic Pain +10 years;
- Irritable Bowel Syndrome +10 years;
- Mental disorder +10 years;
- Meniers syndrome +10 years

Q5 Have you ever taken part in any self-care or self-management support services?

- Mental health

Q6 If you have attended a self-care or self-management support service, what about it was beneficial and what could be improved? I find the one to one support helpful not groups

Q7 What do you think are the barriers that prevent people living with long-term conditions from attending self-care or self-management support services? And what could be done to better support them? My experience with many of the groups there is always someone pushing their agenda and that is why I do not use these services any longer

Q8 If you were designing the perfect support service to help you live better with your long-term condition(s) what would it look like and how would it work? It would be in my home (I am house bound) and would target what I needed not what may be on offer

Q1 What is your age? 65

Q2 What is your gender? Male

Q3 How would you describe your ethnicity? White British

Q4 What long-term conditions do you have and how many years have you been living with each?

- Chronic Neurological +5 years;
- Chronic Pain +5 years;
- Stenosis

Q5 Have you ever taken part in any self-care or self-management support services?

- Expert Patients Programme (EPP)

Q6 If you have attended a self-care or self-management support service, what about it was beneficial and what could be improved? It's non-specific: too general.

Q7 What do you think are the barriers that prevent people living with long-term conditions from attending self-care or self-management support services? And what could be done to better support them? I have mobility issues.

Q8 If you were designing the perfect support service to help you live better with your long-term condition(s) what would it look like and how would it work? More on-line help with the creation of a buddy system. It's difficult to sustain when the course has ended.

Respondent #7

Q1 What is your age? 50

Q2 What is your gender? Female

Q3 How would you describe your ethnicity? White European

Q4 What long-term conditions do you have and how many years have you been living with each?

- Cardiovascular 1-5 years;
- Chronic Neurological 1-5 years;
- Chronic Pain +10 years;
- Mental disorder +10 years

Q5 Have you ever taken part in any self-care or self-management support services?

- Pain Clinic;
- Psychological Services

Q6 If you have attended a self-care or self-management support service, what about it was beneficial and what could be improved?

Respondent skipped this question

Q7 What do you think are the barriers that prevent people living with long-term conditions from attending self-care or self-management support services? And what could be done to better support them?

Fatigue, lack of motivation to approach services

Q8 If you were designing the perfect support service to help you live better with your long-term condition(s) what would it look like and how would it work? Several factors, but mainly specific activities or workshops (that don't last for too long)

Q1 What is your age? 49

Q2 What is your gender? Female

Q3 How would you describe your ethnicity? Black African

Q4 What long-term conditions do you have and how many years have you been living with each?

- Nodular prurigo +5 years

Q5 Have you ever taken part in any self-care or self-management support services? Respondent skipped this question

Q6 If you have attended a self-care or self-management support service, what about it was beneficial and what could be improved?

Respondent skipped this question

Q7 What do you think are the barriers that prevent people living with long-term conditions from attending self-care or self-management support services? And what could be done to better support them?

Lack of follow up care services, lack of confidence to ask for more help (sometimes patients feel they are being burdensome). Sign post all available support services at the initial consultation .

Q8 If you were designing the perfect support service to help you live better with your long-term condition(s) what would it look like and how would it work? I would look at the co-morbidities and how they affect my day to day life, a holistic approach to the whole body instead of one chronic condition. Specialist support e.g. with my condition I would've wanted to see a dietician, allergy specialist. Local community clinics or community centres could host events. Nurses or Public Health experts could facilitate the meeting during the weekend e.g. Saturdays 11.am

Respondent #9

Q1 What is your age? 80

Q2 What is your gender? Male

Q3 How would you describe your ethnicity? White British

Q4 What long-term conditions do you have and how many years have you been living with each?

- Chronic Respiratory +5 years;
- Chronic Neurological +5 years
- Post-stroke paralysis+5 years

Q5 Have you ever taken part in any self-care or self-management support services? Respondent skipped this question

Q6 If you have attended a self-care or self-management support service, what about it was beneficial and what could be improved?
Respondent skipped this question

Q7 What do you think are the barriers that prevent people living with long-term conditions from attending self-care or self-management support services? And what could be done to better support them?
Don't know

Q8 If you were designing the perfect support service to help you live better with your long-term condition(s) what would it look like and how would it work? Daily daytime, domestic assistance (not live-in) to assist my wife, who is my carer.

Q1 What is your age? 63

Q2 What is your gender? Female

Q3 How would you describe your ethnicity? Black British

Q4 What long-term conditions do you have and how many years have you been living with each?

- Cardiovascular +5 years;
- Chronic Pain 1-5 years;
- Diabetes+10 years;
- HIV+10 years;
- Irritable Bowel Syndrome1-5 years;
- Mental disorder +5 years;
- Kidney disease +5 years

Q5 Have you ever taken part in any self-care or self-management support services?

- Diabetes Education and Self-Management for Ongoing and Diagnosed (DESMOND)
- Recently Diagnosed Programme
- Diabetes Self-Management Programme
- Expert Patients Programme (EPP)
- Help On Your Doorstep Service
- Long-term Exercise Programme

Q6 If you have attended a self-care or self-management support service, what about it was beneficial and what could be improved? As being beneficial was portion sized

Q7 What do you think are the barriers that prevent people living with long-term conditions from attending self-care or self-management support services? And what could be done to better support them? Thinking it's a waste of time. More encouragement and positive attitude

Q8 If you were designing the perfect support service to help you live better with your long-term condition(s) what would it look like and how would it work? More leaflets accessible venues time which will be convenient facilitated by an experience person and someone like a patient who is experienced on each topic. Making sure there's an understanding of each condition.

Q1 What is your age? 63

Q2 What is your gender? Male

Q3 How would you describe your ethnicity? Italo-Australian (White Other)

Q4 What long-term conditions do you have and how many years have you been living with each?

- Chronic Neurological 1-5 years;
- HIV+10 years;
- Irritable Bowel Syndrome 1-5 years;
- Mental disorder +10 years

Q5 Have you ever taken part in any self-care or self-management support services?

- Positively UK over fifties wellbeing group

Q6 If you have attended a self-care or self-management support service, what about it was beneficial and what could be improved?

Respondent skipped this question

Q7 What do you think are the barriers that prevent people living with long-term conditions from attending self-care or self-management support services? And what could be done to better support them?

Isolation, outreach and exposure to what can be done, e.g. U=U Campaign

Q8 If you were designing the perfect support service to help you live better with your long-term condition(s) what would it look like and how would it work? My preference is outdoors, walks, exercise, unrushed visits to cultural institutions, social spaces that could make vulnerable people at home and be visible in the community. Making one's home future-proof is high on my list.

Q1 What is your age? 70

Q2 What is your gender? Male

Q3 How would you describe your ethnicity? White British

Q4 What long-term conditions do you have and how many years have you been living with each?

- Chronic Respiratory 1-5 years;
- Chronic Neurological +10 years;
- Chronic Pain +5 years;
- HIV+10 years
- Irritable Bowel Syndrome +10 years

Q5 Have you ever taken part in any self-care or self-management support services? Respondent skipped this question

Q6 If you have attended a self-care or self-management support service, what about it was beneficial and what could be improved?
Respondent skipped this question

Q7 What do you think are the barriers that prevent people living with long-term conditions from attending self-care or self-management support services? And what could be done to better support them?
Lack of support through lack of funding. Not always easy to get appointments

Q8 If you were designing the perfect support service to help you live better with your long-term condition(s) what would it look like and how would it work? When I was first diagnosed my counsellor at the Royal Free put me in touch with a group in Stepney East London. It was a drop in but I could also make appointment for hydrotherapy which was good for my peripheral neuropathy. Advice on benefits. Groups meetings and hot food. Although it was further than the office in Angel I felt better supported there. That is the sort of service I would like to see return

Q1 What is your age? 43

Q2 What is your gender? Male

Q3 How would you describe your ethnicity? Caucasian

Q4 What long-term conditions do you have and how many years have you been living with each?

- Chronic Pain +10 years;
- Mental disorder +10 years;
- Lipodystrophy, peripheral neuropathy, osteoporosis, chronic fatigue +10 years

Q5 Have you ever taken part in any self-care or self-management support services?

- Help On Your Doorstep Service;
- iCope

Q6 If you have attended a self-care or self-management support service, what about it was beneficial and what could be improved? I have tried a number of things, mostly unhelpful. CBT was somewhat helpful to an extent.

Q7 What do you think are the barriers that prevent people living with long-term conditions from attending self-care or self-management support services? And what could be done to better support them?

For me, the main barrier is chronic fatigue, it has really taken my life away from me. I'm struggling to find any help, even after 10 years.

Q8 If you were designing the perfect support service to help you live better with your long-term condition(s) what would it look like and how would it work? The earlier the better for me as my energy is limited, mostly to mornings. Spacing them out is also helpful. Making groups for people with the same issues would also be helpful.

FEEDBACK FROM PROFESSIONALS / PROGRAMME TUTORS

In their own words: The following represents a sample of the feedback we have so far received from healthcare professionals and programme tutors who work with people living with long-term conditions in Islington.

Respondent #14

Q1 What do you think works well about the current self-care or self-management support services available to people living with long-term conditions in Islington? There are a good variety of services on offer including ours and EPP.

Q2 What do you think are the barriers that prevent people living with long-term conditions from attending self-care or self-management support services? And what could be done to better support them? My own view is that people over-idealise professional help - especially when it comes to talking therapies - and expect that others will 'fix' them in a few sessions. I think one important thing is to powerfully illustrate to people e.g. through Social Marketing/Case Studies how healing and empowering it is, and how many opportunities (e.g. Tutoring) it opens up, to take things into your own hands.

Q3 If you were designing the perfect support service to help people live better with their long-term condition(s) what would it look like and how would it work? I think this is really dependent on the type of condition we're considering but I see that EPP and what we do at Talk for Health are both well-researched and have lots of positive features that appeal to people e.g. non-clinical venues, different types of format/times of day to suit different timetables, and that former participants become Tutors/teachers/group facilitators.

Q4 When we develop a new support service for people living with long term conditions what are the most important things we need to include? I think a lot of the EPP programme is excellent especially the parts on how to negotiate and feel empowered with professionals.

Q1 What do you think works well about the current self-care or self-management support services available to people living with long-term conditions in Islington? The participants are able to share their experiences (and learn) from other participants. They also welcome the practical advice and information the course delivers. The opportunity to learn the core skills of goal setting and problem solving. In the Diabetes self-management course they find out and get to understand the condition in some detail and the practical skills to help with that condition. This is information that they have usually not had access to previously.

Q2 What do you think are the barriers that prevent people living with long-term conditions from attending self-care or self-management support services? And what could be done to better support them? Many are working during the day. It would be more useful to them if there were evening/weekend courses available. The courses are not being referred to by health care professionals as much as, I think, they should. There are also post code barriers. Not all boroughs provide the service. There are not enough social media posts advertising courses. They should be promoted with the emphasis on the courses not being boring and dull (which potential participants probably think they will be).

Q3 If you were designing the perfect support service to help people live better with their long-term condition(s) what would it look like and how would it work? I would base it on the Whittington Health Self-Management programmes, plus weekend/evening courses available.

Q4 When we develop a new support service for people living with long term conditions what are the most important things we need to include? As above. But with much more social media involvement to keep the participants activated and in touch with their peers once the course has finished. Q8 Anything else you'd like to say about existing or future self-care and self-management support services in Islington? I think Islington is doing a great job in this field.

Q1 What do you think works well about the current self-care or self-management support services available to people living with long-term conditions in Islington? Open to all. Peer led. Focussed on taking action

Q2 What do you think are the barriers that prevent people living with long-term conditions from attending self-care or self-management support services? And what could be done to better support them? Lack of confidence, lack of understanding of their health issues and what the course could do for them. People attending have increasingly complex range of conditions so regular attendance is difficult - they have health appointments, caring responsibilities and can struggle to put the sessions ahead of other life events. Hard to know what else the team could do within their limited capacity.

Q3 If you were designing the perfect support service to help people live better with their long-term condition(s) what would it look like and how would it work? Range of times and venues. More support for participants from dedicated person in the office who calls and, where necessary gives more practical support to help people attend the first session- working out the buses with them and doing a pre course run through so the person can get there independently. Existing staffing levels make this impossible.

Q4 When we develop a new support service for people living with long term conditions what are the most important things we need to include? Peer led is important. Needs to focus on taking responsibility and making small steps that really matter to the person. A stage two type of session for people who have already done some research for themselves as the more capable people can be hard to retain in the group (even though their input is really helpful). Needs to be staffed adequately. As an ex co-ordinaries I found the huge amounts of work required to get people onto the courses, coupled with constant practical issues and marketing made the job untenable and it led directly to my health crash, from which I am still recovering.

Q1 What do you think works well about the current self-care or self-management support services available to people living with long-term conditions in Islington? giving information to participants on local services for activities (exercise) and support groups has always been well received amongst participants. participants are often surprised when given this information as to how much is actually available locally. as part of the programme it is encouraged for participants to discuss possible support groups that they can create within the group they are already in. Some participants are enthused by this, whilst others are less receptive of the idea. but in all by 'planting' the idea gives the group food for thought about what they can do to support themselves after the programme finishes.

Q2 What do you think are the barriers that prevent people living with long-term conditions from attending self-care or self-management support services? And what could be done to better support them? Those who work during the day or do shift work may find it difficult to attend day-time programmes. Some people may not feel comfortable or feel exposed being part of group. it may be useful for the recruitment of new participants, to invite them to a programme already running so that they can see what goes on or to have podcast/youtube video available to enable them to get some idea of what happens on the programme. Language can be a big barrier within a multi-cultural borough such as Islington.

Q3 If you were designing the perfect support service to help people live better with their long-term condition(s) what would it look like and how would it work? A drop-in service which is available weekly, locally, is accessible and open both in the evening, day-time and weekends to allow individuals to get information about their condition as soon as they are diagnosed. Often I see patients who have been diagnosed with DM for example, who have had to wait a considerable time to be seen by a HCP. These patients when seen are often frustrated and confused about what they should be doing as part of their condition. Information available soon after an individual's diagnosis will be valuable to support compliance and acceptance of their condition. A hotline within the service would be useful too. Often individuals have bombarded themselves with a 100 questions about their condition which they want answered immediately. this service could be available within a non-clinical setting such as local community group, church or a place where the local community meet on a regular basis. I think this question would be a good to ask participants who have attended or just finishing a DSMP by way of a focus group.

continued on the next page...

Respondent #17 continued...

Q4 When we develop a new support service for people living with long term conditions what are the most important things we need to include?

resources such as manpower either employed staff (HCPs, tutors from EPP/DSMP, people living with a long-term condition) or volunteers, or both. Access to reliable information via hard copies and computers available for individual to use. funding to support sustainability of the service which likely needs to be on a rolling basis. Outside speakers to present on different aspects of a long-term condition.

These services offer a life line to individuals with a long-term condition and can help reduce social isolation, increase confidence and meet others with the same condition(s). some individuals attending the programmes have indicated that the use of PowerPoint presentations might be useful rather than tutors reading from a manual

Q1 What do you think works well about the current self-care or self-management support services available to people living with long-term conditions in Islington? The peer support element, and the sessions at the Town Hall.

Q2 What do you think are the barriers that prevent people living with long-term conditions from attending self-care or self-management support services? And what could be done to better support them? From feedback we hear it seems like it would be good to base this in the community and embed the support in community organisations who are already working with residents and may have an on-going relationship with them.

Q3 If you were designing the perfect support service to help people live better with their long-term condition(s) what would it look like and how would it work? This would be co-designed with the people taking part (venue, timing etc). It might be facilitated by both staff and people with lived experience.

Q4 When we develop a new support service for people living with long term conditions what are the most important things we need to include? Inclusivity, cultural awareness, welcoming environment, flexible approach (so if I can't make a session I'm not excluded). Connections with longer term support (if I need/ want it) building on what I've learned to help me continue to manage my condition.