



Action Together

# Care Together

Pre-consultation Engagement Report

September 2016



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## 1. INTRODUCTION

Over the past 2 years, the Care Together programme has sought to progress proposals to radically rethink the way in which Health and Social Care is provided across Tameside and Glossop.

During 2016, the pace of this has escalated and the programme is about to start implementing some of these reforms.

The ambition is *'to dramatically improve the Healthy Life Expectancy of local people whilst also creating a system that is clinically and financially sustainable through a new approach'*

The approach aims to:

- Support local people to remain well by tackling the causes of ill health, support behaviour and lifestyle change, and maximise the role played by local communities.
- Equip those receiving support with the appropriate knowledge, skills and confidence to enable them take greater control over their own care needs and the services they receive.
- Ensure that when illness or crisis occurs, people receive high quality integrated services that are designed around the needs of the individual and, where appropriate, are provided as close to home as possible.

Action Together (and formerly Community and Voluntary Action Tameside), Glossop Volunteer Centre and High Peak CVS have been at the heart of this journey and have played a key role in ensuring that the voices of local people are heard within the programme.

This report captures the latest stage in an engagement journey which commenced in 2014 and will continue during 2016 and 2017.

## 2. EXECUTIVE SUMMARY

This report highlights the findings of the pre-consultation phase of the Care Together Programme during summer 2016 which was led by Action Together (including input from Healthwatch Tameside), and our counterparts in Glossop - High Peak CVS, and Glossop Volunteer Centre.

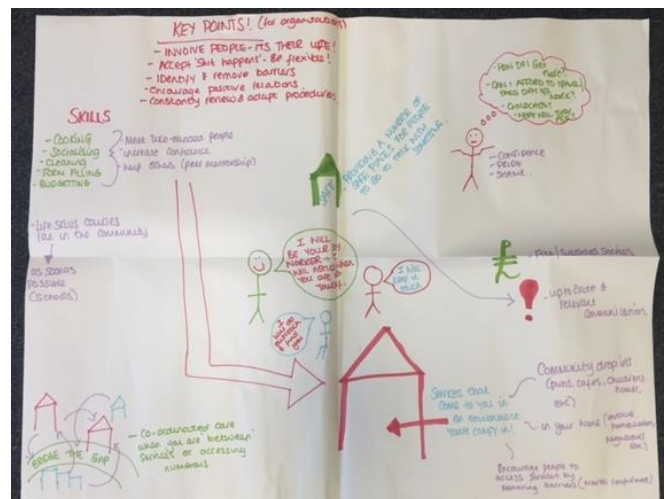
In Tameside and Glossop to date we have engaged 602 local people in conversations around the programme ambition, and the development of specific workstreams.

The approach taken was to work with communities of interest, identity and geography using various Asset Based approaches in order to shift the conversation with communities from 'What should services do better?' to 'What can we do to improve health and wellbeing together?'.

The focus on self-care, peer support, what we mean by a 'good service' and locally based solutions has come through strongly from the people we have spoken to.

In summary, local people gave us the following key messages:

1. *We experience health and social care that is disjointed and delivered in silos, and would welcome more joined up services;*
2. *Our communities have an abundance of 'assets' (people, groups and facilities) which could be better supported and used by local people;*
3. *We think there is much more to be done to prevent ill health, that much of this sits outside conventional health services, and that we want to shape this;*
4. *The way we make decisions about how, when and where to use services is influenced by a range of factors including awareness, accessibility (transport), relevance, staff attitudes and behaviour and whether we get additional support;*
5. *Families and carers play a vital role but we don't always feel supported, valued or involved. The families and carers of adults with a learning disability, feel particularly marginalised by this;*
6. *We want increased focus upon mental health, loneliness and social isolation.*



### **3. METHODOLOGY**

Working with Care Together colleagues, Action Together employed a variety of Asset Based techniques in order to ensure that data was useful and captured detailed feedback from communities of interest, identity and geography, as well as specific services e.g. Stroke, Discharge to Assess and Home First.

The techniques used were:

#### **Focus groups**

By working with voluntary and community groups we were able to reach a large number of service users with particular protected characteristics, particular conditions and experiences of services and from particular geographic communities.

The size of these focus groups was between 6 and 30 people. We were able to give groups a £200 donation for their time and towards the costs of hosting us.

We carried out 32 of these sessions in total, 15 in Tameside and a further 18 undertaken in Glossop by our partners; Glossop Volunteer Centre and High Peak CVS. We reached over 330 local people in this way.

#### **Larger deliberative events**

We facilitated several events for specific groups including:

- A Faith Sector Engagement Event (alongside Faiths United)
- A Voluntary and Community Group Engagement Event
- A Community Engagement Event in Droylsden
- A Community Engagement Event in Ashton.

The focus of these events was to develop a shared understanding of the concepts of Care Together, and develop solutions and aspirations for delivery.

The locality based events were for people from a range of backgrounds and were hosted by larger VCFS organisations namely St Peter's Partnerships - LEAP, and Infinity Initiatives. These events were co-delivered with those groups using an Appreciative Inquiry model. We reached over 100 key community connectors via these events.

#### **1:1 interviews**

Some of the proposals under Planned and Urgent Care required more detailed service user feedback. We undertook four 1:1 interviews with service users involved in the Home First and Discharge to Access services. The interviews, again, used appreciative inquiry techniques in order to create the conditions for patients to highlight what they would like to see, as well as tell us about limitations of the service. People were encouraged to 'tell us their story' so that we have a real understanding of how it 'feels' for people using services. We also talked to 8 members of staff delivering the service about their experience.

#### 4. KEY FINDINGS - WHAT DID PEOPLE TELL US?

- a. **We experience health and social care that is disjointed and delivered in silos, and would welcome more ‘joined-up’ services.**

*“A ‘can do’ approach to community support needs to be encouraged as better multi agency working would help the patient’s journey and save money.”*

- People’s experiences of access to services, diagnosis, treatment and follow up care were mixed. There is variation between individual practitioners within a service as well as variation in the ways that different services operate.

Particular examples of conditions where this was felt included:

- Stroke,
  - Alzheimer’s,
  - Multiple Sclerosis,
  - Fibromyalgia,
  - Mental Health,
  - Breast Cancer.
- 
- The interface and referrals between GP’s, the Hospital and social care were particular areas of concern for people who cited long waiting times, repeating information at each service, and not receiving information that they were expecting, as examples of where things could be improved.
  - People valued being told their treatment date/plan at the time they received a diagnosis.
  - Many people felt that services could be better joined up after diagnosis and treatment and that discharge could be quicker, safer and result in fewer disabilities if things were more joined up and if information on local services (including support groups etc.) were given.
  - People have very different needs in terms of follow-up care. This is partly to do with the nature of their diagnosis but there is also an element of difference in personalities, cultures and life experiences.
  - Professionals we spoke to told us that the quality of referrals were inconsistent because processes, capacity and skills vary between those making referrals and that this needs to be prioritised to be more effective.

They also told us that the use of language needs consideration e.g. ‘referral’ means that expectations to see someone are raised whereas ‘ask an opinion’ does not indicate a visit.

- People want to deal with one person to chase up referrals, appointments etc. This would be especially useful for stroke survivors and people with complex conditions.
- People want care to be better joined up - and some recognise the need for this to include shared data about them.
- People said they valued continuity of care - being able to see the same doctor or nurse every time so they didn't have to keep repeating their history.
- Access was a key concern - including opening hours, out of hours access, transport, waiting times for appointments and making it easier to get home visits.
- In terms of on-line systems people felt that the systems would need to 'talk to each other' first for this to be effective (e.g. GP's having access to hospital notes), that not everyone has a computer, so on-line referrals may not be useful in many cases, texts could be useful for appointments.
- Confidentiality was mentioned as an issue in sharing information between services as the patients themselves often can't remember the details of their treatment.
- Doctors need to ensure that they read notes previous to appointment then they have more time to give to the patient, this is particularly acute when seeing different doctors as patients have to re-tell their story again and again, or receiving a call back asking what the problem is and why they want the appointment. People felt that staying with one doctor would be better.
- Follow up could be improved, and there was a strong feeling that once treatment has happened no-one gets in touch to see how you are 'getting on', some felt that clinical support is withdrawn too quickly.
- People felt that having a specialist unit, where services are all available together would provide a better service. Transport out of a local area is seen by many people as a problem so they welcome the idea that more specialist care could be delivered at a convenient location in their community.
- Support from the physio, OT and socialising with other was seen as a key element of recovery in order to help people 'do more for themselves' stay motivated, and get back to daily living.

*“Being told not to eat before an appointment for blood tests etc. then cancelled at last minute, which can be very difficult when managing other conditions such as diabetes.”*

**b. Our communities have an abundance of 'assets' (people, groups and facilities) which could be better supported and used by local people.**

*“Our GP invited those with COPD to a once a week course for six weeks to explain the condition and how to look after it.*

*As a result, we were linked with the British Lung Foundation and into a Breatheasy group, which now meets at the Methodist Church. St. Luke’s Church.”*

- People highlighted a raft of ‘assets’ that could be enhanced and better utilised to support better health and wellbeing and were keen that the conversation move from a deficit to an asset base. These included:

#### **Physical Assets:**

- There was a strong feeling from Glossop Groups and residents that George House Primary Care Centre is underused and could provide a great space for multi-disciplinary working. There was a view that each locality should have access to the same range of services. This was particularly strong in Glossop where people felt that it was harder for them to get to Ashton to access some services for example; The challenges of getting from Glossop to Ashton if you need urgent care were raised as the same range of services aren’t available in Glossop.
- People highlighted community centres/venues including faith centres as great spaces for services to be delivered and gave examples of where this is already happening to tackle health and the wider social determinants e.g. with the Be Well Service, CAB, Job Clubs, FoodBanks, Exercise classes etc.

#### **The Voluntary, Community and Faith (VCF) Sector:**

- The VCF sector has a clear role to play in supporting local people holistically to improve their health and wellbeing, including tackling the wider determinants of health.
- The sector is well placed to support social prescribing, ABCD and interventions at key life stages e.g. pre-birth, early years, old age and family life.
- There was a strong feeling that the sector needs to be better resourced to support this work both financially and in terms of training, and support from health and care professionals to get the best outcomes for people.
- The complexities for Glossop in terms of funding cuts to the Voluntary Sector and the relationship with Social Care for Glossop residents was seen as a significant challenge for Glossop groups and residents in implementing Care Together.
- There was a clear appetite from groups to work with other sectors and professionals (e.g. GPs), and to create closer working relationships among the VCFS sector.



- There were lots of specific ideas for service development e.g. Home Care, Hospital discharge, mentoring, and social prescribing.

### People and ‘Community’:

- ‘Neighbourhoods’ as defined in Care Together were thought to be too large to resonate with the people we are supporting. Often the VCF sector’s offer is on a ward basis, rather than pan-Tameside.
- Local groups (especially self-help and peer support groups) and activities were seen by many people as a way of getting support to be as healthy as they can by accessing information, managing their own condition and supporting others.
- People feel that their experience could be used to help others.
- People felt that transport and the availability of a range of things to get involved in that are widely known about are important as part of this.

### **c. We think there is much more to be done to prevent ill health, that much of this sits outside conventional health services, and that we want to shape this.**

*“They like coming to groups like Tameside Arts, but it’s not about talking about health issues, more about having fun.”*

- It’s more than just health and care interventions that people say keep them healthy.
- Exercise, healthy eating and social contact are given by many people as ways they stay healthy and look after their wellbeing.
- Libraries, music, the arts and volunteering also feature strongly in comments.
- People value being part of something, and having strong connections with people is important to their wellbeing.
- People are aware of the lifestyle factors that support health and wellbeing, but were just as keen to give examples of things that really matter to them outside of the traditional ‘health’ context.
- People gave examples of how looking after their mental wellbeing was important alongside a diagnosis of a physical illness.
- Managing a long term health condition is seen as important - including taking medications and having regular check-ups.

- Motivation and positive mental wellbeing are seen as important factors in maintaining and improving physical health.
- People highlighted local community groups and family and friends as the key ways that they get information on health and wellbeing outside of their GP or nurse.
- People also valued the contribution of their pharmacy in helping them.
- Finance is seen by some people as a barrier to being healthy - in terms of the cost of participation, the cost of travel to an activity and the cost of healthier food. Other barriers mentioned included physical disability and loneliness.
- Fear of trying something new and being judged by others seems to deter some people from choosing healthier lifestyles.
- Specific examples of the things that people said helped them to stay healthy and well included:
  - Support groups for my medical condition.
  - Volunteering.
  - Having a job.
  - Exercise (including dancing and walking groups).
  - Walking the dog.
  - Diet - eating healthy foods and drinking lots of water.
  - Keeping mentally active - reading, doing puzzles, etc.
  - Mindfulness.
  - Support as a carer and some time away from caring responsibilities.
  - Having regular medical check-ups and taking medication.
  - Going to pharmacy for minor conditions.
  - Holidays and getting outdoors.
  - Art and painting.
  - Good sleep patterns.
  - Listening to music/singing.
  - Good money management.
  - Stopping smoking.
  - Drinking less alcohol.
  - Looking after, each other.
  - Making an effort to talk to other people.
  - Shopping.
  - Pub.
  - Housework/gardening/cleaning.
  - Being outdoors.
  - Grandchildren.
  - Having time off-line.
  - Family and friends.
  - Local groups - including smaller groups and charities
  - Being part of a community.
  - Activities to join in with others.

- Arts and sports activities.
- Libraries.
- Trying new things.
- Help with transport - Ring & Ride, Miles of Smiles and bus passes.
- Exercise.
- Pets.
- Assistive technology - my personal alarm.
- Access to healthcare.
- Local hospital.
- Walk-in centres when you can't get to your GP.
- Doing mental exercises - e.g. crosswords.
- Translation services - language can be a barrier to understanding how to be healthier or explaining a problem.

*“self-help groups - get support - it's good to share”.*

*“It helps to speak to someone who knows what you are going through.”*

*“Additional support services such as support groups and the Be Well Service are not shared with patients, but can be really useful support”.*

**d. The way we make decisions about how, when and where to use services is influenced by a range of factors including awareness, accessibility, relevance, staff attitudes and behaviour and whether we get additional support.**

*“It would be great if GPs had lists of organisations and groups/contacts that you can speak to and brief details of what is available in your local area (not nationally).”*

*“I know several people from the community who will “borrow” medication from family or friends to cope rather than go to the GP or A&E because it is too difficult - the transport, the processes when you get there. GPs and medical staff don't realise just how difficult some people find it to come to the GP for help. It's got to be more approachable and not judgemental.”*

- People consistently highlighted that receiving more information on what is available in their local community was a priority and had great ideas for how information can be disseminated.
- People found that a combination of printed information, friends and family, peer support, community based support groups and specialist NHS teams helped them to understand their diagnosis, its implications and the treatment and post-treatment process.
- The way people use their local health services, as well as out of hours' emergency services, depends to some extent on how they feel about their GP. Where people feel that they are being criticised for their lifestyle choices, particularly relating

to smoking, diet, alcohol and exercise there is evidence that they avoid regular contact with their GP and wait until a point of crisis before accessing health services.

- The use of additional services such as 111, and out of hours seems low, as does people's confidence in using them.
- People commented about the difficulty of getting to Ashton - number and frequency of buses, cost of taxis and parking.
- People also described their experience of the Primary Care Centre as 'difficult', saying that when they had been there they had been sent to A&E -they said that they now go straight to A and E instead.
- Some people said that they use A and E because 'gatekeepers' on reception at their GP practice made it difficult to get an appointment.
- Conversely relatives of people with learning disabilities said going to A&E was difficult because staff wouldn't let them support/speak for the person with a learning disability.
- It was suggested that people going to A and E with a mental health problem didn't get appropriate support.
- People felt that having a range of service in one place would help them to get more joined up treatment e.g. GP, Physio and OT.

*'The [breast cancer] diagnosis is delivered to you in what is known as the "room of doom", anyone with a cancer diagnosis leaves the room with a large brown envelope, and so everyone waiting knows your situation.'*

*"Even in hospital my daughter needs to explain what her disabilities are and what she can and cannot do, it is a tiring business."*

*"Staff are lovely and helpful and friendly", "a lovely way with them, nothing was too much trouble" (People using the Stamford Unit)*

**e. Families and carers play a vital role but we don't always feel supported, valued or involved. The families and carers of adults with a learning disability, feel particularly marginalised by this.**

*"In hospital I wanted my husband to come to the handover because I cannot retain information and couldn't speak, but they would not allow it because it wasn't visiting time".*

*"I potter around the garden as my escape, living with a partner with Alzheimer's is incredibly difficult, until he was prescribed the right medication he didn't really speak*

*anymore, had no interest in what he had been passionate about before and it was like having a bereavement - I missed the person he was.”*

- Many of the carers we spoke to felt that they were not always recognised for the role they play in caring for the person receiving treatment. They felt that they are often experts in the person’s care and what will work best for them, and that this was too often ignored.
- Examples were given where carers were not involved in conversations, but the person’s condition meant that they could not retain the information they were given on their care, appointments being made without speaking to the carer about whether they could practically support the appointment, people not being involved in decision making as a carer when it has been agreed that they should be and assumptions being made that families were able to provide care in the first place when they could not.
- Carers really value additional support including time off from caring, help financially through carer assessments and access to accessible and affordable transport.
- People also told us that at A and E parents/carers have been prevented from supporting adults with a Learning Difficulty or communication disorder during consultations.
- People feel that staff only address physical symptoms and not the additional needs of the patient and that staff in A and E need additional skills in order to support the person as a whole.
- It was also felt that a link person to support the parent and the patient could help this as the role could also look at the wider picture, social, emotional and psychological and that best practice in Children’s wards could be shared.

*“Being able to see Mum (with Alzheimer’s) as ‘just someone I care for’ sometimes [is important to me].”*

*“Isolation is the worst thing... I now take anti-depressants”*

*“Mum goes to day care two days a week, without the Volunteer Drivers this would not happen. I would have no other way of accommodating this care that she needs and work without this service. I have the confidence to know she is safe.””*

*“People find it very difficult to find out what is available for them both in terms of claims/carers support and also patient support... I only found out in year 4 that mum can have a discount on her Council Tax”.*

*“The Memory Clinic and The De-Caff play a huge part in mental wellbeing, these are services that change the lives of patients and carers and should never be underestimated”.*

**f. We want increased focus upon mental health, loneliness and social isolation.**

*“I went to A&E with my sister who was experiencing a breakdown and there was no-one there trained to see her. She cut herself because she knew someone would see her. It is ok if you are physically bleeding, but nothing for mental health and it scared the living daylights out of me.”*

- Mental wellbeing and social connectedness were themes that ran throughout the conversations we have had with people.
- People recognise the link between their mental and physical health, and a large part of this depends on how they connect with others.
- People feel strongly that mental health should be a key element of every service, support for mental illness should be better, and that prevention was key.
- People recognise the importance of their mental wellbeing, and that a large part of how well they feel is linked to their social interactions. Loneliness and social isolation are important features as part of this.
- The availability of crisis support for people with mental illness was felt to be lacking and inconsistent and there was a feeling that Voluntary Sector services are picking up the slack, both in terms of volume and complexity where their resources are already stretched.

*“We need more groups like Anthony Seddon Fund [MH support group], for peer support”.*

*“We have successful health checks for people aged 40-70yrs, through the ‘Be Well’ service to check blood pressure etc. Why don’t we have one for mental health, considering the affect this has on people’s lives?”*

## 5. CONCLUSIONS

As highlighted throughout the report, 6 key messages permeated this phase of engagement, which are:

- a. *We experience health and social care that is disjointed and delivered in silos, and would welcome more joined-up services;*
- b. *Our communities have an abundance of ‘assets’ (people, groups and facilities) which could be better supported and used by local people;*
- c. *We think there is much more to be done to prevent ill health, that much of this sits outside conventional health services, and that we want to shape this;*
- d. *The way we make decisions about how, when and where to use services is influenced by a range of factors including awareness, accessibility (transport), relevance, staff attitudes and behaviour and whether we get additional support;*
- e. *Families and carers play a vital role but we don’t always feel supported, valued or involved. The families and carers of adults with a learning disability, feel particularly marginalised by this;*
- f. *We want increased focus upon mental health, loneliness and social isolation.*

In addition, there were a number of additional cross-cutting findings that are of relevance to the Care Together Programme. These can be summarized as follows:

- People want to be included in design and implementation and have specific and detailed ideas for shaping and changing services based on their expertise by experience.
- People strongly support the work being done to coordinate and join up services and the importance of multi-agency working (including the voluntary sector) to provide better outcomes and save money. It should also be noted that people want to be treated as individuals not in a one size fits all approach or just by their condition and continuity of care also matters.
- Basic things like caring and supportive staff make a big difference and impact on the way people use services. Where people feel that they are being criticised for their lifestyle choices, particularly relating to smoking, diet, alcohol and exercise there is evidence that they avoid regular contact with their GP and wait until a point of crisis before accessing health services.
- The Voluntary, Community and Faith sectors have a clear role to play in supporting local people holistically to improve their health and wellbeing, including tackling the wider determinants of health and interventions at key life stages. This cannot happen without appropriate resourcing including cross-sector relationship building and training. Self-help and peer support groups were seen as particularly important.

- People highlighted the importance of self-care and were keen that the conversation move from a deficit to an asset base - recognising the knowledge base of people living with long term health conditions
- The impact of service changes on those who have protected characteristics needs careful and continued investigation, consideration and response to ensure that they do not inadvertently compound or exacerbate existing discrimination and deprivation.
- Good information sharing and communication matter to people and is often a focus of concern as well as ideas for improvement.
- People understand that keeping healthy and improving wellbeing is about more than just health and care interventions e.g. exercise, healthy eating and social contact and activities (including volunteering).
- Money is seen by some people as a barrier to health and wellbeing - in terms of the cost of participation, the cost of travel to an activity and the cost of healthier food.
- Transport and travel to and from services, including voluntary sector support, is one of the biggest issues, and influences how people experience and use services. Community based support is seen as positive solution to address this.
- There are particular challenges for Glossop residents and groups with a focus on George House Primary Care Centre as a solution.
- People recognised the value of technology in improving access to services and support but want inequalities related to this (e.g. IT literacy and access) to be addressed.



## 6. RECOMMENDATIONS

As the Care Together Programme Progresses towards implementation we make the following recommendations:

### 1. Close the feedback loop and move the conversation on:

- This is the third time since 2014 that we have spoken to people about the programme, there is a clear message from people that they want to know what has changed as a result of what they said, and what the next steps are for the programme.
- People are keen to shape the future and we need to harness this in the genuine spirit of co-production as the Care Together Programme progresses towards implementation of a new Model of Care, local people should be actively involved in co-designing new approaches, supporting their implementation and evaluating their success.
- Examples of where this could happen quickly include:
  - Phased implementation of the Patient Activation Measure (PAM)
  - Mapping existing provision that would underpin an asset based health model and approaches such as Social Prescribing, Self-Care and Peer Support.
  - Developing the Integrated Neighbourhood models in partnership with local people and groups
  - Supporting the improved utilisation of community facilities such as the George House Primary Care Centre in Glossop.

### 2. Hear the Unheard:

- Although engagement to date has been extensive, there are some groups that remain under-represented and unheard.
- During the next phase of Engagement, we will undertake targeted engagement to capture the insight of the groups which include, but are not exclusive to:
  - Children and Young People
  - Black British, African and Caribbean Communities
  - White European Communities (and particularly Polish Communities)
  - People who live in Hattersley, Longdendale, Mossley and Audenshaw.

### 3. Share the learning:

- We need to ensure that the valuable insight we have from this engagement is shared across the system, and is acted on by all agencies that are involved in the Care Together programme.
- This insight needs to be presented in a way that is useful to people working across systems at each level from strategic to operational.

- The Care Together Programme should identify the most appropriate way to ensure that this happens in a meaningful way including the development of a clear action plan linked to these conclusions and recommendations.
- The specific issues raised in relation to carers, mental health, poverty and equality issues and transport require dedicated attention and championing as current and planned activity in relation to these complex areas is less visible and possibly under-explored at present.

#### 4. Utilise Asset Based Approaches:

- Utilising the power of local groups to get to people that we wouldn't usually hear from works. We need to carry on with this approach, and develop towards co-produced proposals where the resource to get involved is available to the groups that are best able to contribute.
- Using asset based methodology Appreciative Inquiry, motivational interviewing etc. is key to providing the culture shift from 'what should you do for me?' to 'what can we do together?' both in terms of within the communities we serve and in terms of staff and services.
- We need to capture feedback from our organisational assets - our staff and volunteers running services, recognise their contributions and ensure that there is an avenue for them to shape the changes and 'be the change they want to see'.
- We need to further identify the opportunities for the Voluntary, Community and Faith sector both in service delivery, and as a conduit to marginalised communities in order to shape a health, care and wellbeing offer that meets the aspirations of communities of interest, identity and geography. There are opportunities for this particularly through the development of Integrated Neighbourhood Teams and Social Prescribing as well as the engagement program.

## **7. APPENDICES:**

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