

# Carer Engagement 2017

**London Borough of Croydon**

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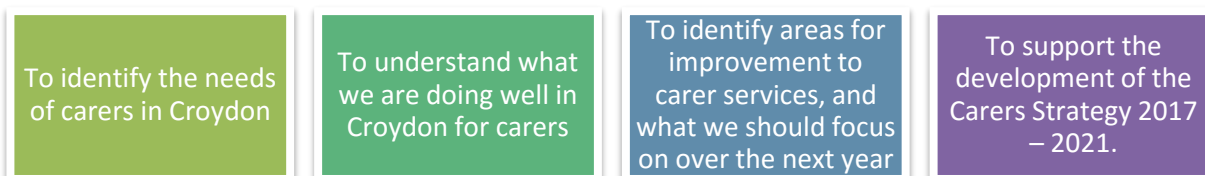
## Contents

Contributors .....	2
Acknowledgements.....	2
Executive summary .....	4
Introduction .....	6
Objectives .....	7
Methods.....	7
Results and discussion .....	8
Table one – engagement respondents .....	8
Survey results.....	8
Figure one – Number of caring hours by gender .....	9
Figure two – Relationship between carer and cared for person by gender .....	10
Figure three – Three types of support that make the biggest impact on a carer’s role in the last 12 months .....	11
Figure four – Respondent breakdown by age.....	12
Figure five – Responses to what we are doing well in Croydon .....	12
Table two – Responses to how caring impacts on a carer’s lifestyle.....	13
Table three – Responses to what Croydon can do better. ....	15
Recommendations from the survey .....	18
Focus group results & recommendations.....	18
Mental health carers.....	18
Learning disability .....	19
Black & minority ethnic carers.....	20
Young adult carers .....	21
Mixed carers group .....	21
Conclusion.....	22
Recommendations .....	24
Next steps .....	25
References .....	26
Appendix One – Online Survey .....	27
Appendix Two – Focus Group Schedule.....	32

## Executive summary

Carers are invaluable to our health and social care network. They are our experts by experience. In Croydon, there are 33,683 carers, which makes up 10% of the total population of Croydon. Approximately 42% of carers in Croydon are male and 58% are female. The majority of carers are aged between 45 and 64 years old (ONS, 2011), Carers in Croydon save the local economy an estimated £654 million per year (Bucker & Yeandle, 2015). In 2015, the State of Caring survey reported that 82% of carers report that caring negatively impacts on their health (Carers UK, 2015). Providing support to carers is the best way to help prevent a care breakdown, which can result in an emergency admission for the cared for person and/or the carer (RCGP, 2013).

## Objectives



## Methods

Two methods of data collection were utilised: an online and paper survey and seven focus groups. These were co-designed with the support of the nine carer organisations in Croydon. To increase uptake, the nine carer organisations disseminated the online survey link out to their client databases. Of the focus groups, six were conducted in existing groups to ensure that carers who may not usually attend engagement events were heard. These groups were: black and minority ethnic carers, young adult carers, carers of someone with a mental illness, carers of someone with a learning disability, and a group of mixed carers. This was then followed-up with an additional focus group at the Carers' Support Centre with a mixture of carers.

## Results

322 people participated. Of these, 262 people responded to our online / paper survey and 60 carers attended the seven focus group sessions. When asked to state the three types of support that had the greatest impact on a caring role in the past 12 months, the top three were: a break from caring (45%), having a friend or relative who is able to help (38%), and having health professionals that listen and understand their caring role (33%). This is a slight change from the 2015 survey which showed the top three types of support were; benefits (44%), and break from caring (48%), and having the right information available (35%).



## Recommendations

1. To provide more flexible opening times for carer support services
2. To provide services for carers in different areas of the borough
3. To provide equitable financial support for carers
4. To have more access to a break from caring e.g. activity days or affordable respite provision
5. To provide carers with more support in employment e.g. promote flexible working, provide a carer support group for working carers
6. Better promotion of the current services for carers in the borough
7. To provide support for carers after their caring role has ended
8. Feedback to the CCG the issues relating to IAPT services in Croydon
9. Work with GP practices to identify carers earlier
10. To promote the commissioned services clearly stating that they are funded by Croydon Council
11. To work with the hospitals in Croydon to enable better communication during patient discharge
12. To provide one-to-one support and group activities for young adult carers and promote awareness of young adult carers to the local colleges and sixth form colleges.
13. For health, social care and all council staff to have a better understanding of a caring role
14. To provide carer assessments and financial support to parent carers of someone under 18 years

### Next steps...

1. Supporting providers to implement the recommendations from this report where possible

2. Working with colleagues to implement the recommendations from this report where possible

3. Updating the work plans of the relevant staff in the council

4. Using the information presented to inform and develop the Carers Strategy 2017 - 2021

5. Continuing to work with carers to shape services in Croydon

## Introduction

Croydon Council continues to support carers in Croydon. The council recognises their valuable contribution to the health and social care community. This support has been enhanced by the Care Act 2014 by providing local authorities in England with a legal responsibility to assess the needs of carers, support their eligible needs and promote their wellbeing. In addition to this, the Care Act requires councils to provide personalised support, which has been recently highlighted in a report by Croydon Healthwatch looking into carers of the over the age of 65 years (Croydon Healthwatch, 2016) support. Furthermore, the NHS has pledged its support to carers, with the publication of the NHS England's Commitment to Carers 2014, and the NHS Five Year Forward View 2014 (NHS England, 2014a; NHS England, 2014b). Both these documents recognise the role of a carer as an expert by experience and the need to engage with and support them.

The Care Act defines a carer as *"an adult who provides or intends to provide care for an adult needing care... [who] is not under or by virtue of a contract, or as [part of] voluntary work."* (Care Act 2014, p.10)

This change in legislation comes at a time when council and NHS resources are faced with new financial challenges and opportunities to change the way they work. Croydon Council alone has £50 million of savings to make over the next two years in addition to the increasing pressures on social care associated with an ageing population.

The 2011 census shows that there are currently six million unpaid carers in England and Wales. Unpaid carers save the UK economy £119 billion per annum (University of Leeds, 2011), with the latest research estimating that carers save the economy £132 billion. In Croydon, carers save the local economy an estimated £654 million per year (Bucker & Yeandle, 2015). In 2015, the State of Caring survey reported that 82% of carers report that caring negatively impacts on their health (Carers UK, 2015). Providing support to carers is the best way to help prevent a care breakdown, which can result in an emergency admission for the cared for person and/or the carer (RCGP, 2013). Moreover, new research indications that for every £1 spent on carers, creates £4 of long-term cost savings (RCGP, 2015).

In Croydon, there are 33,683 carers, which makes up 10% of the total population of Croydon; this is higher than many other London boroughs including Merton, Lambeth, Southwark and Lewisham. Of these, approximately 19,000 are in employment, of which over 2,000 are in employment and provide more than 50 hours of unpaid care per week. Approximately 42% of carers in Croydon are male and 58% are female. The majority of carers are aged between 45 and 64 years old (ONS, 2011), however new research from Age UK estimates that nationally, there are over 2 million carers aged 65 years and over, an increase of 300,000 from 2009 (Age UK, 2016). In Croydon, this is around 6,000 carers (ONS, 2011) and it is likely that many of these carers do not identify themselves as a carer. Croydon has around 2,500 young adult carers; those aged between 16 and 24 years and out of our total number of carers, approximately 7,000 provide over 50 hours of unpaid support each week (ONS, 2011).

Previously, Croydon Council's Carer Engagement 2015 identified that 40% of respondents were able to identify themselves as a carer within six months of providing care, which is significantly better than the two year national average (Carers Trust Cambridgeshire, 2015).

Croydon Council has conducted this carer engagement with carers in Croydon as well as those with an interest in carers to better understand the needs of Croydon's carers and to see if these needs are being met either by the community, local community and third sector organisations, health and social care services, and / or another service. In addition to this, it aims to identify any areas of opportunity for development or change to better support carers in Croydon. To do this, the council worked with The Whitgift Foundation's Carers' Information Service, which runs the Carers' Support Centre, Mind in Croydon, Croydon Mencap, Croydon Parents in Partnership (PIP), Off the Record (who provide our young adult carers' service) Horizon Care and Welfare Association, Croydon Neighbourhood Care Association (CNCA), and Help for Carers.

This engagement is an Adult Social Care project and focused on the following groups of carers; adult carers, young adult carers, carers of people with mental illnesses, carers of older people, black and minority ethnic carers (BME), and carers of people with a learning disability. Young carers are outside the scope of this report; councils are obligated to support this group following the Children & Families Act 2014, as a result, young carers' services are commissioned by Children's Services in Croydon. It should also be noted that the recommendations generated in this report are from carers, and will be used by the council to aid the development of their relevant work plans. For the purpose of this engagement activity, the following objectives were developed.

## Objectives

- a) To identify the needs of carers in Croydon
- b) To understand what we are doing well in Croydon for carers
- c) To identify areas for improvement to carer services in Croydon, and from this, what we should focus on over the next year
- d) To support the development of the Carers Strategy 2017 – 2021.

## Methods

To assist this engagement exercise, two methods of data collection were utilised: an online survey to be disseminated by all stakeholders, including; Help for Carers, the Whitgift Foundation, Croydon Mencap, Off the Record, Alzheimer's Society, Horizon Care & Welfare Association, Mind in Croydon, CNCA and PIP; and seven focus groups with the support of Help for Carers, Horizon, The Whitgift Foundation, Croydon Mencap, Mind in Croydon and Off the Record. In order to generate responses regarding the entire local offer for carers, and not just regarding council commissioned services, the questions were designed to obtain a response on the whole model of support. In addition to reducing the confusion of carers having to differentiate between commissioned and non-commissioned services, this enables the council to create a better understanding of the wider picture of support available locally to carers, which therefore allows us to identify any gaps.

The online survey was coproduced with the nine organisations providing carers' support in Croydon (Carers' Information Service, Mind in Croydon, Alzheimer's Society, Croydon Mencap, Croydon Parents in Partnership, Horizon Care and Welfare Association, CNCA, Off the Record, and Help for Carers) and was conducted for a six week period from September 2016. To increase uptake, the nine carer organisations disseminated the online survey link out to their client databases, this included the 2,053 carers registered with the Carers' Information Service for their electronic newsletter, the

Council’s communications team promoting the survey via their website and social media, and the partners of the Carers Partnership Group disseminating the online survey. All responses were anonymous and to encourage people to complete the survey and to reduce the number of questions asked. To prevent duplicate responses from individuals, the survey was set to allow one response per IP address. This may have disadvantaged carers who relied on shared computers to complete the survey, however paper versions of the survey were made available for carers.

The survey utilised a mixture of multiple choice and open questions. These questions were largely based on Care Act outcome domains for carers and the national Think Local Act Personal (TLAP) questionnaire for carers. A copy of the survey schedule is in appendix one.

In addition to the online survey, seven focus groups were facilitated with five different groups of carers, these were; carers in the black and minority ethnic (BME) community, carers of people with learning disabilities, carers of people with mental illnesses, young adult carers and two mixed group of carers. The majority of the focus groups were held at existing carers’ groups to increase participation rates and to ensure that the views of those who would not usually engage with the local authority were heard. In addition to this, a focus group was held at the Carers Support Centre. The focus group schedule was coproduced with carer organisations in Croydon and the groups were either facilitated by the council or co-facilitated by the council and a third sector representative. They were designed to be semi-structured, therefore allowing the facilitator to adapt to each individual situation, see appendix two for an example of the schedule. The focus group schedule was based on the TLAP questionnaire for carers and carers were asked to identify areas for improvement in Croydon. The recommendations in this report have therefore been generated by carers in Croydon.

## Results and discussion

In total, 322 people participated in this engagement exercise. Of these, 262 people responded to our online / paper survey, and 60 carers attended the seven focus group sessions; see table one for a breakdown of focus group attendees and those who responded to the online survey.

**Table one – engagement respondents**

Focus group type	Number of attendees/respondents
Mixed carers (2 focus groups)	30 (14 + 16)
Carers from the BME community	8
Carers of people with mental illnesses	4
Carers of people with learning disabilities	6
Young adult carers (2 focus groups)	12 (6 + 6)
<b>Total</b>	<b>60</b>
Survey respondents	262
<b>Engagement total</b>	<b>322</b>

## Survey results

The following results are from the 262 carers in Croydon that responded to the carers’ survey. These results help to answer the objectives of this report which are to; a) identify the needs of carers in Croydon; b) understand what we are doing well in Croydon for carers; c) identify areas for improvement to carer services in Croydon, and from this, what we should focus on over the next year;



and d) support the development of the Carers Strategy 2017 – 2021. Of those that responded to this survey, 81% were female, whilst 19% were male. Nationally it is known that approximately 42% of carers in Croydon are male and 58% are female (ONS, 2011), however our local data shows that 79% of carers that are known to our carers' register are female and 21% are male. This shows that the responses to this survey are proportionate to the carers that are known to the register. However, this highlights the need for additional efforts to identify and support more carers. In addition to this, of those that responded to this survey, the majority (69%) care for one person, while 27% of the carers reported caring responsibilities for two people, 3% stated that they support three people and 1% stated that they support four or more people.

Of the respondents, 51% of female carers reported providing over 50 hours of support, while 31% of male carers reported providing this much support. Of those who provide 20 to 49 hours of support, 40% were male and 30% were female. The majority of carers who responded to this survey were providing over 50 hours of support (48% in total), we know that the majority of carers in Croydon are providing fewer than 19 hours of support (66% of carers in Croydon (ONS, 2011)). The results of this survey are disproportionate to the carer population in Croydon as a whole, this could show that fewer carers providing under 19 hours of support are being identified or are willing to respond to research. As a result, this survey is not representative of the carer population in Croydon, however, this does show that the carers that require the most support from services are well represented in this survey. Figure one shows a breakdown of the number of hours spent caring by gender in Croydon.

**Figure one – Number of caring hours by gender**

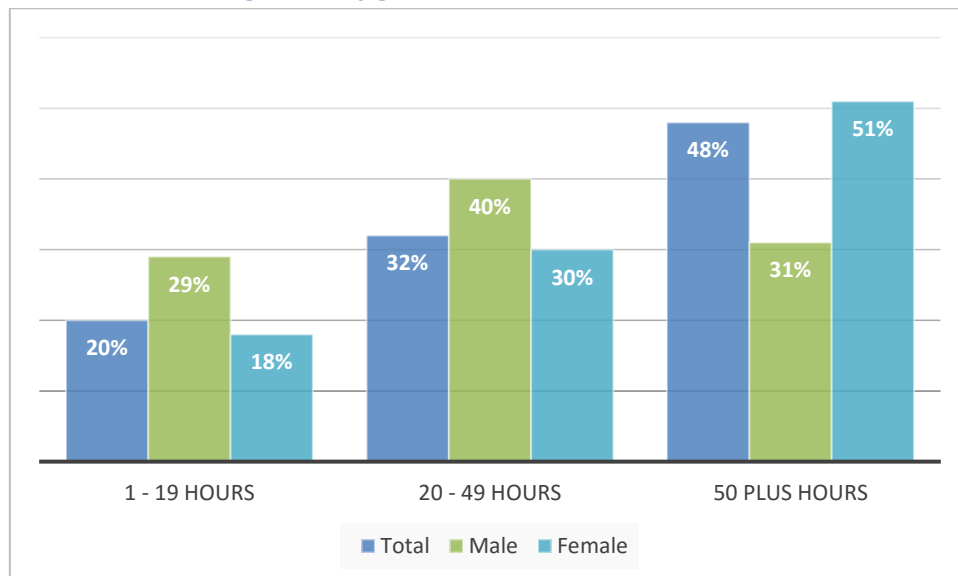
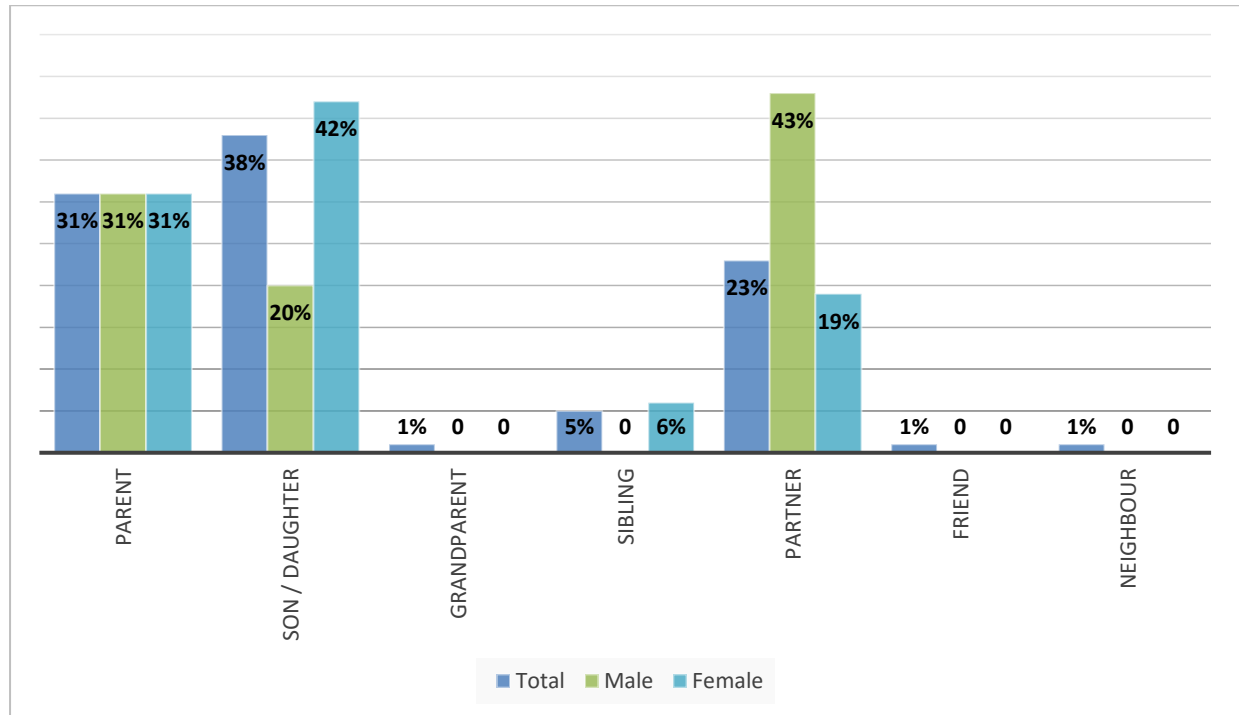


Figure two shows the relationship between the carer and the cared for person by gender. Interestingly, it shows that 43% of the male carer respondents were supporting their partner, while 19% of the female responds were supporting a partner. Female carers were more likely to be supporting a son or daughter (42%), whilst the number supporting a parent was the same (31%).

Figure two – Relationship between carer and cared for person by gender



When asked to state the three types of support that had the greatest impact on a caring role in the past 12 months, the top three were: a break from caring (45%), having a friend or relative who is able to help (38%), and having health professionals that listen and understand their caring role (33%). This is a slight change from the 2015 survey which showed the top three types of support were; benefits (44%), and break from caring (48%), and having the right information available (35%). Having the right information available is now in position four (29%) while benefits was reported by 20% of respondents. Having health professionals that listen has risen by 10% from 2015. Figure three shows the full breakdown of the types of support that had the greatest impact on caring in the past 12 months. When compared to the Think Local Act Personal (TLAP), Making it Real for Carers guidance, this correlates well with this evidence. The TLAP guidance shows that carers want reliable support staff, active and supportive communities, and supportive and understanding healthcare professionals (ADASS, 2013).

Figure three – Three types of support that make the biggest impact on a carer’s role in the last 12 months

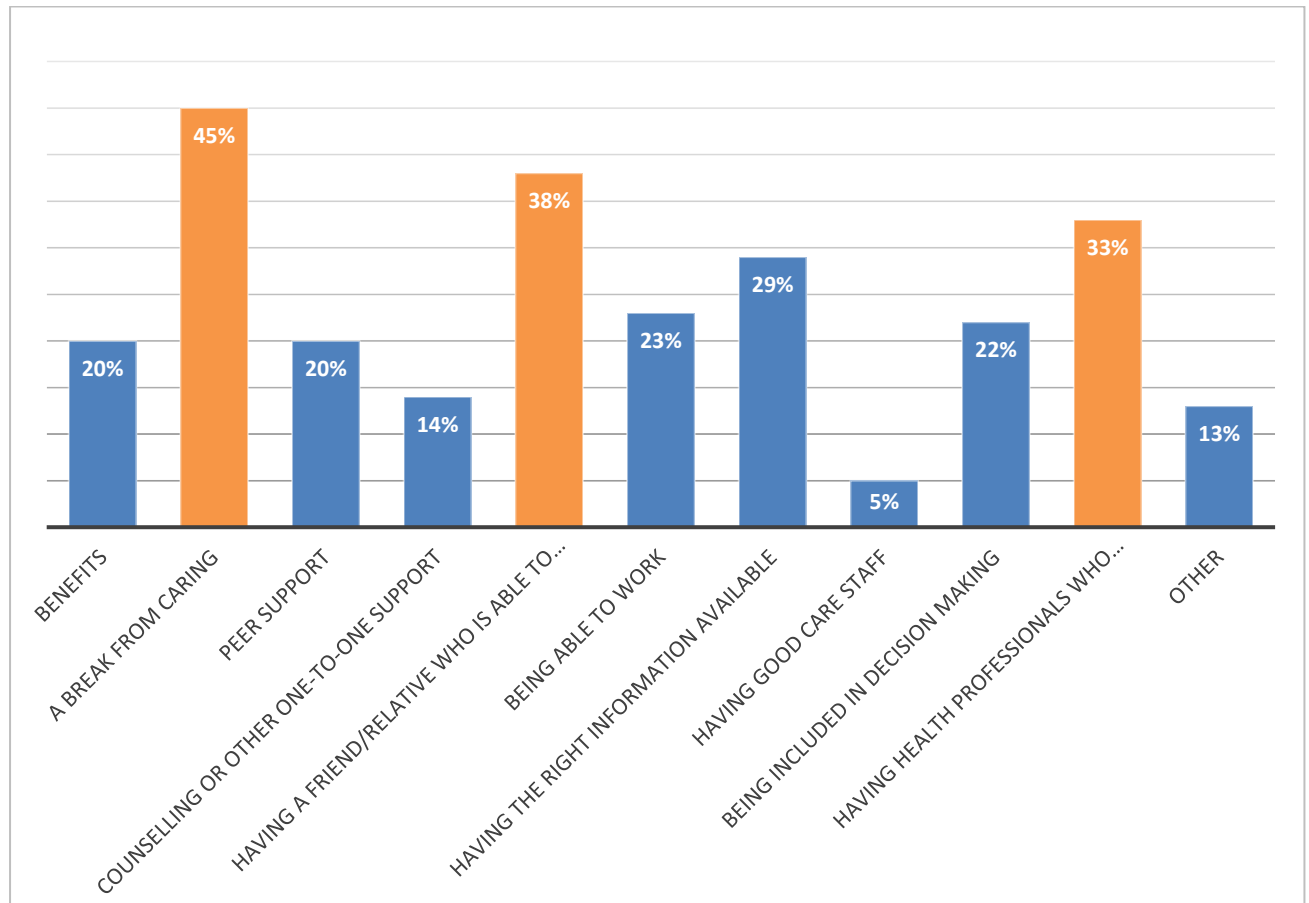
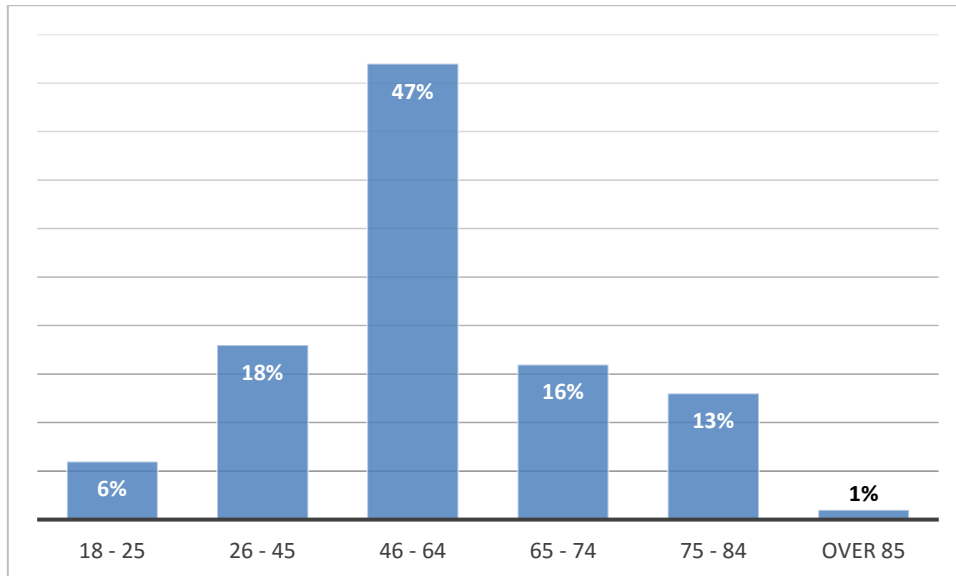


Figure four shows the carer respondents by age. Forty seven percent are aged between 46 and 64 years. In Croydon, 62% of carers are aged between 35 and 64 years, with 17% over 65 years (ONS, 2011). This survey has a higher proportion of respondents that are over 65 than compared to the carer population in Croydon, with 30% of respondents over 65. In addition to this, 59% of respondents defined themselves as white, 17% identified as Black / Caribbean / African / Black British, 7% were Asian and 10% preferred not to say. This correlates well with the demographic ethnicity of Croydon as identified in the census which showed that 55% of residents are White, 16% are Asian and 20% are Black / Caribbean / African / Black British (ONS, 2011). Future engagements should seek responses from the Asian community to ensure a better representation.

Figure four – Respondent breakdown by age



In 2015 Croydon Council asked carers if “The services available for carers in Croydon are enough to meet my needs” and “I feel supported within my community”. On average carers responded neutrally to both (neither agreed nor disagreed). This year 46% of respondents stated that they feel supported within their community while 44% disagreed that the support services available in Croydon were enough to meet their needs. It should be noted however that the researcher noted some confusion with this question as some carers did not understand what was meant by support services in Croydon and changed their response to ‘agree’ when they did. This shows that further clarification is required for future engagements.

Figure five – Responses to what we are doing well in Croydon



Table two – Responses to how caring impacts on a carer’s lifestyle

Theme	Description
<p><b>1. Prevented from maintaining relationships</b></p>	<p>When we asked carers whether caring has impacted on any part of their life carers stated that they were unable to maintain relationships due to the longevity of support they provide for their cared for. Having a good support network from friends and families often help carers to cope long term and without this support it is inevitable that carers’ can feel lonely. For example:</p> <p style="text-align: center;"><i>“...I’m unable to maintain an active social life.”</i></p> <p style="text-align: center;"><i>“I do not have time to engage with other members of my family (child, grandchildren, sister) or to enjoy exercise or social activities.”</i></p> <p>Making it real for Carers (2013) found that carers often wanted the space to be someone other than a carer. Carers want to be able to have a life outside of the care and therefore rely on the services provided and support from friends and family to help them achieve this. This theme also links with the theme of being prevented from recreation.</p>
<p><b>2. Prevented from recreation</b></p>	<p>Carers stated that their caring precluded their ability to participate in recreational activities. This response is understandable due to many carers being full time carers, often relying on support from friends and family. These responses were taken from the survey:</p> <p style="text-align: center;"><i>“I never seem to have enough time for myself and even when I can get away I feel guilty.”</i></p> <p style="text-align: center;"><i>“...cannot get out or continue with my past activities...”</i></p> <p>Often carers feel less inclined to ask for help, as they’ve been coping for years. These responses reflect the way carers can often want time to themselves yet feel guilty because of it. These responses correlate with the high amount of carers requesting more respite or better flexibility regarding respite. This finding complements the Think Local Act Personal guidance Making it Real for Carers (2013) which shows that carer want to have a reliable workforce which enables them to have some time for themselves.</p>
<p><b>3. Prevented from supporting another child or adult with support needs</b></p>	<p>Carers found the care they gave impacted heavily on their ability to support another child or adult. Carers of either their son or daughter made up around 38% of the sample; this type of carer held one of the largest percentages in the engagement survey when asked whom they provide care for. Here carers were precluded from providing what they felt to be sufficient support to either a child or another adult for whom they provide care. For example, one carer stated:</p> <p style="text-align: center;"><i>“Caring for my daughter consumes every minute of my day... My other daughter does not get the time and attention she needs...”</i></p>

	<p>From the survey, we also know that 27% of respondents stated that they supported another adult with a support need and 3% stated that they provide support for an additional 2 adults with support needs. This could indicate that the cared for person's package of support is insufficient for their needs.</p>
<p><b>4. Prevented from employment</b></p>	<p>This theme is especially relevant as the Office for National Statistics found that 62% of carers are at peak working age (50-64 years old) which is potentially an individual's peak earning age. Often carers cannot find employment that fits around the needs for their cared-for. In the survey some carers stated that they were prevented from finding work or working as much as they wanted to due to their duties of being a carer, for example:</p> <p style="text-align: center;"><i>"I gave up my career that took 3 decades to build to take on guardianship..."</i></p> <p style="text-align: center;"><i>"My caring role affected all areas including work..."</i></p> <p>These responses are especially pertinent as Valuing Carers (2015) released a report that highlighted that carers in Croydon are worth over £654 million to the local Croydon economy. With many carers willing to work but have stopped due to their caring responsibility, this suggests that Croydon may need more employers that are flexible and understanding regarding carers.</p>
<p><b>5. Prevented from maintaining a habitable home</b></p>	<p>This theme relates to how much time carers have to keep their house tidy. Some carers were unable to do so due to the number of other 'chores' there were to do, whilst others stated it was more difficult because they did not live with the cared for person, which therefore meant that they did not have enough time. E.g.:</p> <p style="text-align: center;"><i>"...sometimes it's (sic) not possible to keep the house neat..."</i></p> <p style="text-align: center;"><i>"I have less time to attend to the daily chores of living as I don't live with the person I am (a) carer for."</i></p> <p>Not being able to maintain a habitable home can be very personal to some people and can negatively impact on their wellbeing. Not having enough time to undertake these tasks correlates with the Think Local Act Personal guidance Making it Real for Carers (2013) which shows that carer wants to have a reliable and supportive workforce which enables them to have some time for themselves.</p>
<p><b>6. Prevented from education</b></p>	<p>Carers being prevented from education and training they want to engage in means that they are often not allowed to be anything but carers. If carers want to attend education and training courses they should be able to and be allowed to be a carer too. For example:</p> <p style="text-align: center;"><i>"Would like to study but no time [sic]."</i></p>

	<p><i>"I would like to do an advance/ specialist computer course...the hours clash with my caring role."</i></p> <p>From the responses, it can be seen that most carers want to be able to participate in education/training but they simply do not have enough time. Education not only allows carers to learn something new, but it also allows them to enhance their skills and thus increase their employability if they are seeking employment.</p>
<p><b>7. Prevented from maintaining nutrition</b></p>	<p>Carers reported finding it hard to maintain nutrition due to the demands of the support they give. Reasons for this include forgetting to eat, not having enough time to eat properly, not having enough time to cook properly or as they would like. For example, some carers stated:</p> <p><i>"You do not have time to cook good healthy food..."</i></p> <p><i>"At times I forget to eat as I am busy taking care."</i></p> <p>These responses seem to interlink with what was said in the Making it real for carers (2013). The report went on to explain that carers need "Time and support to manage their own health needs." Furthermore, this has a potential impact on the cared for person's health if these carers are responsible for providing meals. Malnutrition is thought to be the fourth largest potential source of cost saving for the NHS (BAPEN, 2010) and Brotherton <i>et.al</i> (2012) state that CCGs should focus on community nutrition education to improve care in the community in order to save lives and money. Furthermore, a recent report by Public Health England (2017) states that malnutrition results in 65% more GP visits, 82% more hospital admissions and 30% longer hospital stays.</p>

**Table three – Responses to what Croydon can do better.**

Theme	Description
<p><b>1. Better understanding of a carer's role</b></p>	<p>This theme is especially pertinent following the Care Act 2014; carers want to be recognised by healthcare professionals, have their needs understood and have their opinions taken into consideration. This knowledge can be helpful to healthcare professionals as carers know the person they support best. Here, carers stated that healthcare professionals should have a better understanding of a carer's role. For example, carers stated:</p> <p><i>"Training staff to deal with carers in a compassionate way."</i></p> <p><i>"I'm constantly questioned about my motivation of benefits, therapies and support. There is little to no understanding and empathy with people working with parent carers in Croydon."</i></p>

Unfortunately, this theme is not unfamiliar. In 2014 Carers UK reported that 19% of their respondents felt that their caring role was not recognised by healthcare professionals, however, they also found that 20% of carers found that hospital staff valued and recognised their role.

This theme is in relation to the opening times of the Carers' Information Service and other support services. Here, carers stated that they would like the support services for carers, such as peer support and training to be open on the weekends and/or open for longer during the week, as this will help carers who work. In addition to this, carers stated that they would like services to be available across the borough and not just in the centre, for example, carers said:

**2. Flexible opening times & borough wide access**

*"...evening courses to include working parents."*

*"Most of the support seems to be available in the day time - no good if you're working."*

*"I would love to do some gentle exercise or something much nearer home..."*

This theme links with the *Making it Real for Carers* guidance regarding the flexibility of support for carers (2013). It is well known that carers mainly look for help and support at a time of crisis, so it is imperative that they have access to information and advice when they need it.

**3. Increase respite / activity days**

Carers want to be able to take a break from their caring role. Respondents stated that in Croydon, there could be an increase in the provision of respite and/or activity days as this would help carers to meet some of their personal outcomes. These include; day centres, activity days, activity groups, short breaks, affordable respite. For example, one carer wrote:

*"...additional funding for carers to have breaks and to be able to study."*

This finding complements the Think Local Act Personal guidance *Making it Real for Carers* (2013), specifically the three themes: active & supportive communities, flexible & integrated support, and having a reliable workforce.

**4. Flexible employment support**

Carers want to be able to return to work after caring or to be able to work part or full time whilst managing caring responsibilities. To do this, carers need understanding employers, who value their contribution, whilst recognising the need for flexible working. This links with the *Making it Real* guidance for carers which shows that carers want active and supportive communities, being able to care and continue their personal life. For example, one carer stated that they would like to see:

*"...flexible or home working opportunities."*



Employment can be particularly important and useful for carers. In Croydon, 77% of our carers are between 18 and 64 years old, and therefore considered working age adults (Carers' Information Service, 2015). This links with national evidence which suggests that 62% of carers are aged between 45 and 64 years of age, and 31% of carers are in paid work (Carers UK, 2015).

**5. Promote current services**

This theme links with themes 1, 2, 3 and 4; promoting services will help healthcare professionals better understand the role of carers and having professionals who better understand carers could mean that they get identified and support sooner. In addition to this, it may enable carers to find services that they are able to attend and provide them with information regarding activity days or information and advice that they were otherwise unaware of. This could make a positive impact on a carer's role and potentially identify carers in the workplace sooner. This theme was indicated by respondents, either due to stating that better promotion of services should exist, or asking for services that are already provided, which they would know about if they were better promoted. For example, carers stated:

*"Improve access to counselling."*

*"I have used the carers centre etc. Very good. I think these kinds of services need to be more widely publicised especially by h/c professional at the point of contact/diagnosis."*

Counselling is already available through the Carers' Support Partnership, provided by Mind in Croydon, this service is specifically for carers. Therefore better promotion would have prevented this response.

**6. Support for after caring**

In this theme, carers stated that more could be done to support carers who were no longer caring. This is an area for development in Croydon. It is known that when carers cease being carers for whatever reason, it is usually after a significant number of years whereby they may have been out of work and lost a number of social connections. For example, one carer said:

*"...what happens after life after caring [sic]"*

Each year around 6,000 carers transition into and out of a caring role annually (RCGP, 2013), many of these will do so without any support required, however there will still be some carers who require additional support.

**7. Financial Support**

In this theme it transpired that carers often wanted more financial support. The financial support would enable carers to be more independent by allowing them to spend the money on things that they want such as; extra support, education and other things they may need. In addition to this, carers stated that they wanted carer assessments and financial support for parent carers of someone under 18 years old. Carers stated:

*"To have more support on benefits or any kind of financial help."*

“...additional funding for carers to have breaks and to be able to study.”

Personalisation of support is something that many NHS and local authorities are striving to achieve and forms the basis of the Care Act 2014, the NHS Five Year Forward View and the NHS’s Commitment to Carers. In addition to this, in Croydon, Healthwatch reported that a more personalised approach to support is a real opportunity for carers to benefit from. The report also explains that carers should know about their rights and entitlements when it comes to allowances (Croydon Healthwatch, 2016).

## Recommendations from the survey

From this survey, carers in Croydon would like the following recommendations:

- For health and social care staff to have a better understanding of a caring role
- To provide services for carers in different areas of the borough
- To provide carer assessments and financial support to parent carers of someone under 18 years
- To look into more flexible opening times for carer support services
- To have more access to a break from caring e.g. activity days or affordable respite provision
- To provide carers with more support in employment
- To increase promotion of the current services provided by the council and by other organisations
- To provide support to carers after their caring role has ended

## Focus group results & recommendations

A summary of each focus group is below. In total, 60 carers attended a focus group (see table one for the breakdown of attendees) and these have been split into the four client groups. These are mental health, learning disabilities, BME carers, and mixed carers. These results help to answer the objectives of this report which are to; a) identify the needs of carers in Croydon; b) understand what we are doing well in Croydon for carers; c) identify areas for improvement to carer services in Croydon, and from this what we should focus on over the next year; and d) support the development of the Carers Strategy 2017 – 2021. As seen with the online survey results above, a number of the recommendations from the focus groups link with the national guidance documents such as *Making it Real for Carers* (ADASS, 2013), *NHS England’s Commitment to Carers* (NHS England, 2014a) and *Supporting Carers in General Practice* (RCGP, 2013).

### Mental health carers

The group started by introducing themselves and discussing the person they support. The group was made of carers that support someone with a mental health problem. The relation to the person was

a mixture of carers supporting their partner and their children (over 18 years old). The group discussed the types of services that they had accessed in the past year. These were Mind in Croydon's peer support group and activities such as yoga and outings.

The group discussed the positive support services in Croydon that they found most helpful, these were:



The group then discussed the areas in their lives that were affected by their caring role. These were being prevented from education, volunteering or recreation, maintaining a habitable home, maintaining nutrition, being prevented from working and maintaining relationships. This was due to reasons such as the cared for person's behaviour being threatening at times, the cared for person not allowing others into the family home, fatigue from caring preventing them from employment, training, volunteering, keeping the house tidy, not being able to sit at the family table together for meals, and an increase in the amount of washing per day due to the cared for person wearing a number of garments per day which then have to be cleaned.

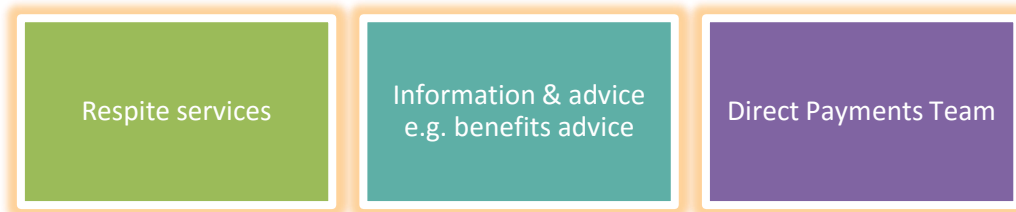
The group then discussed the gaps in Croydon, or where we can improve our services. The carers discussed what would have the greatest impact on their role as a carer the suggestions for the coming year were:

- IAPT services should respond more promptly
- GPs should promote carers services and refer carers to the Carers' Support Centre on George Street
- Better social work retention
- Improved access to respite opportunities e.g. longer breaks

### Learning disability

The group started by discussing the relationship between the carer and cared for person, in this group, the carers were supporting their children who were over the age of 18. The group then discussed the types of service they had accessed over the past 12 months. These were a carer assessment, Mencap's services, support with completing forms, information & advice, day activities, the Direct Payments Team at Croydon Council and peer support.

From this, the group then agreed the three types of support that were most beneficial to their caring role. These were:



This then led to a discussion on areas that have been affected by their caring role. These were being prevented from education, volunteering or recreation; maintaining nutrition, and prevented from working. The reasons for this included not having the time due to their caring responsibilities and requiring extra supervision at meal times.

The group then discussed the gaps in Croydon, or where we can improve services. The carers discussed what would have the greatest impact on their role as a carer, the suggestions for the coming year were:

- 
- The diagram shows four horizontal light blue bars, each preceded by a small blue square icon. The text in the bars is as follows:
- More advocacy for carers
  - Improvements to day centre (respite)
  - Better retention of social workers
  - More thought of people with learning disabilities when planning and building new homes

### Black & minority ethnic carers

The group started by discussing the relationship of the carer to the cared for person. This included supporting their children, grandparent, parent, friend and aunt. From this the group then discussed the types of support services that they had accessed in the past 12 months and the services that they thought were most useful in their caring role. These were;



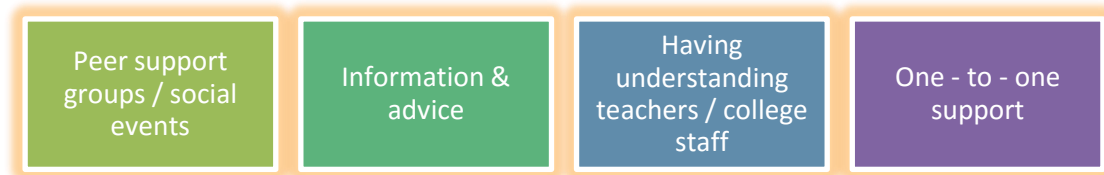
This then led to a discussion on the areas of the carer's life that were affected by their caring role. The carers said that they were not able to engage in recreation, education or volunteering as they are in the home, it is easier to support them. In addition to this, carers felt supported by Horizon's respite service which enabled them to do other things. They were also unaffected by being able to keep a habitable home as they could do this whilst the cared for person was in their home. The carers were unable to take paid employment as a result of their caring role, they would however be able to take part-time employment or employment with flexible hours, however it was recognised that this was difficult to find.

From this, the carers discussed the gaps in the current model, and the areas that should be focused on within the next year. Carers suggested that the council should focus on the following:

- Availability of longer breaks
- Better promotion of existing services
- Availability of overnight support for the cared for person

### Young adult carers

The groups started by discussing the relationship of the carer to the cared for person, this included carers supporting a sibling, parent and grandparent. From this the groups then discussed the services that they had previously accessed, understandably, these were quite limited to the support previously provided by Off the Record, benefits advice and adult social care in the council. The groups discussed the types of support that have been useful to them, these were;



Following this, the group then discussed the areas that Croydon should focus on when developing a service, these were;

- Promote awareness of young adult carers to college and sixth form college staff
- More activity groups / social events
- Provide one-to-one support

### Mixed carers group

These two groups started by discussing the person they support. The majority of people were supporting a parent with Alzheimer's or frailty or they were supporting a partner. In the past 12 months, the group had accessed a variety of services commissioned by the council which included: council occupation therapy, Alzheimer's Society dementia café, carers' support group, training at the Carers' Support Centre, Mind in Croydon's services, Asperger's parent support group, IT training from Help for Carers, a Time4Me payment from Croydon Council, activity groups, advocacy support and a carer assessment.

From this, the group then discussed the support services in Croydon that they found useful or positive in the past 12 months. These were:



This then led to a discussion on areas that have been affected by their caring role. These were being prevented from education, volunteering or recreation, maintaining a habitable home, maintaining nutrition, prevented from working and maintaining relationships. The reasons for this included not being able to attend courses, employment or recreation due to their caring role and not having the time for personal relationships due to their caring role.

Following this, the group discussed the main areas that should be focused on over the next 12 months. One area identified was to improve hospital discharge. This relates to Croydon Healthwatch's research that shows older people want better support during and after hospital discharge (Croydon Healthwatch 2016). The other suggestions were;

- Develop a working carers' support group
- Improving access to council respite e.g. being able to book in advance
- Improve hospital discharge
- More education programmes in mental health and dementia

## Conclusion

In total, this engagement has had responses from 322 carers who provide support in the London Borough of Croydon. Of these, 262 responded to the online survey and 60 carers attended the carer focus groups that were hosted and/or co-facilitated by Mind in Croydon, Horizon Care and Welfare Association, Croydon Mencap, the Whitgift Foundation, Off the Record and Help for Carers.

Results from the online survey indicated 59% of respondents defined themselves as White British, 17% identified as Black / Caribbean / African / Black British which correlates well with the demographic ethnicity of Croydon as identified in the census which showed that 55% of residents are White British and 20% are Black / Caribbean / African / Black British (ONS, 2011). Fifty one percent of female carers reported providing over 50 hours of support, while 31% of male carers reported providing this much support. Of those who provide 20 to 49 hours of support, 40% were male and 30% were female.

The three types of support that these carers reported as having the greatest impact on a caring role in the past 12 months were: a break from caring (45%), having a friend or relative who is able to help (38%), and having health professionals that listen and understand their caring role (33%). This is a slight change from the 2015 survey which showed the top three types of support were; benefits (44%), and break from caring (48%), and having the right information available (35%).

Feedback from the online survey and the focus groups were generally favourable to the carer organisations in the borough. All groups including Alzheimer's Society, Help for Carers, Mind in Croydon, Croydon Mencap, Off the Record, the Whitgift Foundation, Horizon Care and Welfare Association, Croydon Council's Direct Payments Team, Occupational Therapies Team. Carers stated that the staff from all these organisations were very friendly, helpful and welcoming. Conversely, there were some negative comments regarding other colleagues in the council who are not in social care. This could therefore indicate a potential training opportunity. In addition to this, it was noted that the council could do more to support flexible work opportunities by encouraging organisations to be more understanding of carers. In addition to this, carers thought that the council was doing well in the following area: counselling for carers, good signposting, respite / respite provisions, training or education for carers and social service support.

Carers stated that they were unable to achieve various aspects of the 8 outcome domains from the Care Act. Not every carer was unable to achieve every outcome, however the majority of carers were unable to achieve at least one of the outcome domains. These were: being prevented from maintaining relationships, being prevented from recreation activities, being prevented from supporting another child or adult with support needs, being prevented from employment, education or training, being prevented from maintaining a habitable home, and being prevented from maintaining nutrition.

During the focus groups it was identified that carers were largely unaware of the different services that Croydon Council commissions for carers and the amount of money spent on these services. Moreover, this misunderstanding led many carers to hold the belief that the council does not provide much support for carers. When corrected, the group were impressed with the amount of support commissioned by the council. Elsewhere, it was identified that some carers were requesting activities that were already available in the borough. This is a recurring theme from the previous year's engagement. This shows that more needs to be done in Croydon to promote the services available and to better promote the funding organisation.

During the focus groups and from the online survey, carers reported that their caring role affects their life in many ways. The survey and focus group questions were aligned to the Care Act personal outcomes for carers which all showed areas of impact on the carers. These themes were: being prevented from education, volunteering or recreation; maintaining a habitable home, maintaining nutrition, prevented from working and maintaining relationships. Reasons varied from exhaustion due to caring, not having enough time to do other things and certain disabilities of the cared for person requiring additional support e.g. during meal times.

When asked what Croydon could do better, seven themes transpired from the online survey, these were: better understanding of a carer's role, flexible opening times and borough wide access, increased respite / activity days, flexible employment support, promote current services, financial support and support for after caring.

During the focus groups, when asked what could be improved in Croydon, a number of themes developed across the groups. These were: increased respite, support for carers in employment, better promotion of available services, develop a service for young adult carers including one-to-one support and activities for young adult carers. These, in addition to the recommendations developed from the carers' survey, led to the development of the recommendations for future practice in Croydon.

## Recommendations

The recommendations from the carers in this engagement are:

1. •To provide more flexible opening times for carer support services
2. •To provide services for carers in different areas of the borough
3. • To provide equitable financial support for carers
4. •To have more access to a break from caring e.g. activity days or affordable respite provision
5. •To provide carers with more support in employment e.g. promote flexible working, provide a carer support group for working carers
6. •Better promotion of the current services for carers in the borough
7. •To provide support for carers after their caring role has ended
8. •Feedback to the CCG the issues relating to IAPT services in Croydon
9. •Work with GP practices to identify carers earlier
10. •To promote the commissioned services clearly stating that they are funded by Croydon Council
11. •To work with the hospitals in Croydon to enable better communication during patient discharge
12. •To provide one-to-one support and group activities for young adult carers and promote awareness of young adult carers to the local colleges and sixth form colleges.
13. •For health, social care and all council staff to have a better understanding of a caring role
14. •To provide carer assessments and financial support to parent carers of someone under 18 years



## Next steps

Following this research, over the next year Croydon Council will work towards;

Updating the work plans  
of the relevant staff in  
the council

Supporting providers to  
implement the  
recommendations from  
this report where  
possible

Working with colleagues  
to implement the  
recommendations from  
this report where  
possible

Using the information  
presented to inform and  
develop the Carers  
Strategy 2017 - 2021

Continuing to work with  
carers to shape services  
in Croydon

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## Appendix One – Online Survey

### Carers' Survey 2016

It has been a year since the Care Act put carers firmly on the agenda, with local authorities having a duty to assess carers' needs and support their eligible needs. Croydon Council are currently updating their Carers' Strategy, and would greatly appreciate your feedback. Your comments will help shape the services that are commissioned by the council and therefore help to support you other carers. If you provide unpaid support for someone with support needs, please could you spend a few minutes completing our short survey? The survey should take around 10 minutes to complete. Your response is completely anonymous as we will not ask for any of your personal information. Your comments will help shape Croydon's Carers' Strategy for the next 5 years. We look forward to hearing from you!

1: Who do you provide support for? (If you provide support for more than one person, please just think about the person you provide the most support for.)

Please tick one option only

- |                          |                          |                          |
|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| A person<br>under 18     | A person 18<br>to 64     | A person<br>over 65      |

2: What is their primary support need?

Please tick one option only

- |  |  |
|--|--|
| <input type="checkbox"/> Adult physical            | <input type="checkbox"/> Adult mental health       |
| <input type="checkbox"/> Adult Learning disability | <input type="checkbox"/> Child learning disability |
| <input type="checkbox"/> Child mental health       | <input type="checkbox"/> Child physical            |
| <input type="checkbox"/> Dementia / Alzheimer's    | <input type="checkbox"/> Elderly                   |
| <input type="checkbox"/> Palliative                |  |

3: What is their relationship to you?

Please tick one option only

- |                                      |   |
|--------------------------------------|---|
| <input type="checkbox"/> Parent      | <input type="checkbox"/> Son / daughter |
| <input type="checkbox"/> Grandparent | <input type="checkbox"/> Sibling        |
| <input type="checkbox"/> Partner     | <input type="checkbox"/> Friend         |
| <input type="checkbox"/> Neighbour   |   |

4: In addition to the person described above, do you provide support to anyone else with a support need?

Please tick one option only

- Yes - 1 other     
 Yes - 2 others     
 Yes - 3 plus     
 No

5: In total, approximately how many hours of support do you provide per week to someone with a support need? (This can include any other people that you may support.)

Please tick one option only

- 1 - 19 hours     
 20 - 49 hours     
 50 plus hours

6: In the last 12 months, what 3 types of support have made the most impact on your caring role? **Please select only 3 choices.**

Please tick all that apply

- |   |   |
|---|---|
| <input type="checkbox"/> Benefits   | <input type="checkbox"/> A break from caring  |
| <input type="checkbox"/> Peer support   | <input type="checkbox"/> Counselling or other one-to-one support                                  |
| <input type="checkbox"/> Having a friend/relative who is able to help                             | <input type="checkbox"/> Being able to work   |
| <input type="checkbox"/> Having the right information available                                   | <input type="checkbox"/> Having good care staff   |
| <input type="checkbox"/> Being included in decision making for the care of the person you support | <input type="checkbox"/> Having health professionals who understand what you do and listen to you |
| <input type="checkbox"/> Other  |   |

Please Specify

7: In the past 12 months, has your caring role affected your ability to engage in recreational activities?

Please tick one option only

- Yes     
 No     
 Don't know

8: In the past 12 months, has your caring role affected your ability to engage in education, training, work or volunteering?

Please tick one option only

- Yes     
 No     
 Don't know

9: In the past 12 months, has your caring role affected your ability to maintain a habitable home?

Please tick one option only

Yes       No       Don't know

10: In the past 12 months, has your caring role affected your ability to manage your nutrition?

Please tick one option only

Yes       No       Don't know

11: In the past 12 months, has your caring role affected your ability to look after a child that you have responsibilities for?

Please tick one option only

Yes       No       Don't know

12: In the past 12 months, has your caring role affected your ability to provide support for another adult with support needs that you care for?

Please tick one option only

Yes       No       Don't know

13: In the past 12 months, has your caring role affected your ability to develop and maintain family / other significant personal relationships?

Please tick one option only

Yes       No       Don't know

14: In the past 12 months, has your caring role affected your ability to make use of necessary facilities or services in the local community?

Please tick one option only

Yes       No       Don't know

15: If you answered yes to any of the questions between 7 and 14, could you please describe how you have been affected? If you answered no to all of all of the questions between 7 and 14, please write N/A.

16: Do you agree or disagree with the following statement? The services available for carers in Croydon are enough to meet your needs.

Please tick one option only

Strongly  
agree

Agree

Neither agree  
nor disagree

Disagree

Strongly  
disagree

17: Please explain your answer.

18: Do you agree or disagree with the following statement? I feel supported within my community. E.g. friends, family, GP, carer services.

Please tick one option only

Strongly  
agree

Agree

Neither agree  
nor disagree

Disagree

Strongly  
disagree

19: Please explain your answer.

20: What are we doing well for carers in Croydon?

21: What could be improved on and what is missing in Croydon for carers?

22: In the next 12 months, what carers' support would you like Croydon Council to

23: What is your gender?

Please tick one option only

- Male       Female       Other

23.1: Please Specify

24: Which age group do you fit into?

Please tick one option only

- |                                   |                                  |
|-----------------------------------|----------------------------------|
| <input type="checkbox"/> Under 18 | <input type="checkbox"/> 18 - 25 |
| <input type="checkbox"/> 26 - 45  | <input type="checkbox"/> 46 - 64 |
| <input type="checkbox"/> 65 - 74  | <input type="checkbox"/> 75 - 84 |
| <input type="checkbox"/> Over 85  |                                  |

25: What is your ethnicity?

Please tick one option only

- |  |   |
|--|---|
| <input type="checkbox"/> White               | <input type="checkbox"/> Mixed -White & Black-<br>African/Caribbean     |
| <input type="checkbox"/> Mixed-White & Asian | <input type="checkbox"/> Any other mixed background                     |
| <input type="checkbox"/> Asian               | <input type="checkbox"/> Black / Caribbean / African /<br>Black British |
| <input type="checkbox"/> Any other group     | <input type="checkbox"/> Prefer not to say                              |

26: Do you consider yourself to have a disability?

Please tick one option only

- Yes       No

**If you answered "No" to question 26 then you have finished the questionnaire**

27: If yes, are you registered disabled?

Please tick one option only

- Yes       No

Thank you for completing our survey.

## Appendix Two – Focus Group Schedule

### Carers' Focus Group

1. Who do you provide support for?

*Facilitator's note: write responses on flipchart*

2. What type of support have you accessed in the last 12 months? E.g. Information & advice, help accessing benefit, a break for you, counselling

*Facilitator's note: hand out post it notes, collect responses on a flipchart*

3. In the last 12 months, what 3 types of support have been the most helpful to you to support you in your caring role?

*Facilitator's note: collect responses on flipchart, tally results*

- *Benefits*
- *A break from caring*
- *Peer support (talking to someone who does the same role as you), support groups*
- *Counselling or other one-to-one support*
- *Having a relative/friend who is able to help*
- *Being able to work*
- *Having the right information available*
- *Having good care staff*
- *Being included in decision making for the care of the person you support*
- *Having health professionals who understand what I do and listen to me*

4. In the past 12 months, has your caring role affected your ability to engage in activities that you may like to do such as recreational activities, education or volunteering? If yes, what haven't you been able to do?

5. In the past 12 months, has your caring role affected your ability to (if you would like to) maintain a habitable home or nutrition? If yes, how?

6. In the past 12 months, has your caring role affected your ability to look after a child that you have responsibilities for or another adult with support needs? If yes, how?

7.

- a. In the past 12 months, has your caring role affected your ability to take paid employment or work? If so, how?

- b. (Optional) Has your caring role ever impacted your ability to work or take paid employment?

8. What is missing for carers in Croydon & what are we doing well?

*Facilitator's note: hand out post it notes, draw a table on the flipchart, allow people to stick suggestions on the flipchart.*