

# Age UK Croydon Personal Independence Coordinator Service

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*Independent Evaluation, November 2021*

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## Authorship and acknowledgments

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## Executive Summary

### Key outputs

- 1,127 clients accessed the service in the last year, with 909 referrals within the period<sup>1</sup>
- 1,382 goals were set in the last year (Aug – Sept 20-21)
- 18,507 contacts took place<sup>2</sup>
- 671 guided conversations took place<sup>3</sup>

### Key outcomes

- 98% of clients improved their mental wellbeing in the last year (94% over the last 3 years)
- 99.6% of clients achieved at least one of their wellbeing goals (over the last year)
- 83% of all wellbeing goals were achieved (in the last year)

### Client satisfaction

- 99% of clients say they would recommend the service to friends and family (over the last three years), and 100% in the last year.

### Key findings

- The service is **highly valued by patients and health professionals**, who believe it makes a valuable contribution to the improvement of patient care
- In particular, the service has had positive, indeed, **transformative effects on the mental wellbeing of older people**, and on their wider quality of life
- Healthcare professionals strongly believe that **the service reduces costs** as well as **improving care** across the system, although ‘the jury is still out’ on reducing hospital admissions
- As part of the wider changes and the development of the ICN, the service could have a key role in **transforming the culture of the local NHS**

### Key recommendations

- The service may be less well-understood outside of the healthcare system and might benefit from **clearer communication with the VCS**
- Focusing the service on the **‘upstream’ support for patients** (especially at primary care level, and before hospital admissions seem most likely) may prove even more effective – although the resources to do this would need to be considered carefully
- Further work on **structuring the end of PIC relationships with clients** may further increase the longevity of mental wellbeing benefits

<sup>1</sup> The number of Organisations and People who have either been referred or who have been referred earlier but who have had a contact within the time period requested.

<sup>2</sup> Numbers of contacts with, or on behalf of clients, by clients themselves or organisations representing them - this includes the first Referral contact and any subsequent contacts for that Referral in the requested date range. Contacts undertaken in Home-Support type services or clubs and groups are not included.

<sup>3</sup> This number excludes people who had guided conversations prior to the period, or who had yet to receive guided conversations, while the number of people using the service includes those who were receiving the service but had already had their initial guided conversation.

- There is work to be done on ensuring that referrals are made responsibly and appropriately to the service, especially where this relates to severe mental illness. It is hoped that the new mental health PIC service will help to alleviate this, but stronger boundaries and clearer rules for referrers will also be a critical success factor.
- The PIC service does not currently have a waiting list. In order for this to remain the case, some **further exploration of managing caseloads between individual PICs** would be of value, especially in terms of ensuring that there are clear boundaries and 'cut-offs' in terms of what is, and is not within their remit.
- The project has an **extremely rich dataset** which could be analysed in a number of ways to understand more about the client group, and the effectiveness of particular goals or interventions. However, to do this, specialist support would need to be given to AUKC.

## Introduction

This report analyses the impact and effectiveness of the Age UK Croydon Personal Independence Coordinator (PIC) Service, and makes recommendations for its future development.

## About this report

### Scope and methodology

The research takes a highly qualitative approach, taking account of the subjective experiences, as well as objective outcomes, for:

- Clients who use the service, based on NHS Friends and Family survey data, case studies, and telephone surveys
- Frontline professionals from, NHS primary care, the voluntary sector, and other social sector professionals, drawn from in-depth interviews
- Age UK Croydon staff delivering and managing the service through focus groups and individual interviews

It also presents key performance metrics including:

- Outcomes results using the nationally recognised Short Warwick Edinburgh Mental Wellbeing Scale
- Project-specific measures, such as the achievements of goals and enablers

NHS Friends and family data was gathered and transcribed by Age UK staff (as is standard across friends and family data gathering in the NHS). Care was taken to ensure that this was undertaken by staff members who had not previously been involved with the interviewed client. In order to ensure full transparency, Age UK Croydon also commissioned Healthwatch Croydon to contribute to this report, and undertake a set of telephone interviews via a call centre to ensure any potential for bias was minimised. Outcomes figures were provided by Age UK Croydon. Key performance figures and outcomes were provided by Age UK Croydon, based on data in their database, including the graphs in the appendix.

### The purpose of this evaluation

Using this data, the report outlines key successes, analyses critical success factors, and summarises learning from the project, outlining some key areas of further development for the service. It is hoped that the report might make a positive contribution to learning and development of the One Croydon Alliance and the Integrated Care Network as a whole.

The report builds on previous evaluations undertaken by Healthwatch Croydon (of the Croydon service), and the Nuffield Trust (of the national PIC programme pilot), which found that the PIC service adds significant value to the health and social care system.<sup>4</sup>

‘The findings highlight how the PICP intervention extends beyond ‘signposting and care navigation’. While these are important, it is the combination of the shared care planning focused on what’s important to the older person, ongoing care coordination and support,

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<sup>4</sup><https://www.ageuk.org.uk/our-impact/programmes/integrated-care/>

and multi-disciplinary working involving the PICs that has been critical to achieving the benefits experienced by older people and primary care.<sup>5</sup>

### Funding and authorship

This evaluation has been funded by the NHS Clinical Commissioning Group, commissioned by Age UK Croydon, and undertaken by Alex Evans Community Consulting. A contributory survey was conducted by Healthwatch Croydon, and this is included as an Appendix.

### History of the Project

A promising Phase 1 pathfinder Personal Independence Coordinator (PIC) project was run by Age UK in Cornwall in 2015, and Phase 2 saw a roll-out to several other Boroughs across the UK. In Phase 3, Age UK jointly funded the project in Croydon in 2016 with the Croydon Clinical Commissioning Group (CCG), as part of the CCG's plans to support 'whole-system transformational change.'<sup>6</sup> In 2017, the service was further developed as part of the One Croydon Alliance (the partnership between Croydon Health Services Trust, South West London CCG, Croydon Council, GP Collaborative, South London and Maudsley Charitable Trust and Age UK Croydon) and rolled out across the Borough. The service has continued to be based in GP Practices across the Borough, with PICs taking part in GP Huddles and Multi-Disciplinary Team meetings.

### Why it was commissioned

For the CCG, some key drivers for commissioning the service included the need to:

- Take a more holistic and patient-centred view of healthcare
- Recognise and address the potential impact of non-medical issues on medical issues if they are left unchecked
- Reduce any unnecessary burden on healthcare systems by ensuring appropriate use of both primary and acute care
- Address national NHS integration strategies, and the movement towards Integrated Care Services, where health and social care are brought together
- Make better use of the value that the voluntary and community sector can provide to people's health and wellbeing

### The Aims of the Project

The main aims for the service set out by the CCG are:

- To improve the wellbeing of older people in Croydon
- To improve the experience of older people who frequently use health and social care services in Croydon
- To reduce costs pressures on the Croydon healthcare system
- To ensure people live as independently as they can, for as long as possible

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<sup>5</sup> 'Blended evaluation of Phase 2 of the Personalised Integrated Care Programme Summary report', 7th March 2018, Summary report by Yvonne Fulwood. <https://www.ageuk.org.uk/globalassets/age-uk/documents/programmes/personalised-integrated-care-programme/summary-picp-blended-evaluation-report-270618-ppt-2.pdf>

<sup>6</sup> 'Impact of the Personal Independence Coordinators Service', Age UK.

## The Croydon Context

According to the ONS, Croydon has one of the highest populations of residents over 50 (at 122,000, or 32%) in London. The Borough becomes more densely populated, poorer, and more ethnically diverse in the North, as it gets closer to central London. Parts of the Borough are in the 5% most deprived in the country, while others (towards the south of the Borough) are not in the top 20%, and there is a high level of inequality between the North and South for all types of deprivation.<sup>7</sup> Additionally, Croydon, along with Sutton and Kingston, has one of the highest rate of care homes in the UK per capita.<sup>8</sup> This means Croydon often becomes a destination for older people from elsewhere in London who are less able to manage independently as they grow older - presenting particular challenges for NHS services.

The PIC service has been a key component in the development in Croydon of the Integrated Care Network (ICN) model of care, which divides the Borough into six localities to provide proactive and preventative care, closely integrating social care, with some specific commissioned services from the community and voluntary sector alongside the health system. At the time of evaluation, a new 'ICN+' model has been trialled in Thornton Heath (Croydon North West) and is about to be scaled up across the rest of the Borough. This brings together a much wider range of community and voluntary sector partners.

While the service originally took referrals solely from GP surgeries via the multi disciplinary team meetings (huddles) , in 2019, a decision was made to encourage the addition of community referrals to the PIC service from a whole range of partners. This is designed to ensure that older people who are not known to GPs can access help, perhaps at an earlier stage in their journey, before wellbeing issues become pressing healthcare matters. Again, this is designed to reduce the inappropriate use of acute services, and to an extent, primary care. The PIC model developed by Age UK has also been used to create a Mental Health PIC Service in Croydon, run by Mind in Croydon and Croydon BAME Forum.

A key part of the role of the individual PICs is to ensure they are fully networked into the health and social care system. They attend and participate in multi-agency GP Huddles, Multi-Disciplinary Teams, Virtual Talking Points, Complex Care, Rapid Response, and ICN and ICN+.

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<sup>7</sup> <https://www.ageuk.org.uk/wp-content/uploads/sites/8/2020/03/SWL-care-home-data-pack-2019.pdf>

<sup>8</sup> <https://www.ageuk.org.uk/wp-content/uploads/sites/8/2020/03/SWL-care-home-data-pack-2019.pdf>

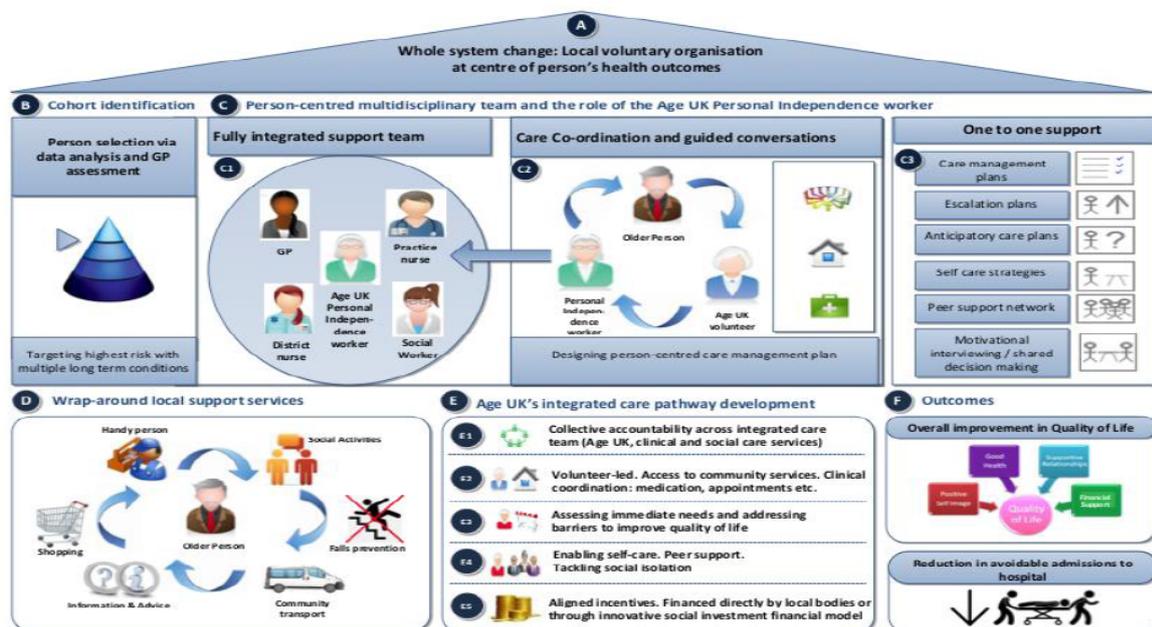
## About the Service

### The Age UK Pathway

1. We use risk stratification to identify a specific cohort of older people with multiple long-term conditions who are vulnerable to unplanned admission to hospital.
2. Using a 'guided conversation', an Age UK Personal Independence Co-ordinator draws out the goals that the older person identifies as most important to them.
3. Together, they create a care plan which brings together services from across the health, social care and voluntary sectors that are appropriate for the older person's need. Effectively, the services 'wrap around' the older person, with the aim of reversing the cycle of dependency.
4. Age UK volunteers can be assigned to help older people achieve their goals
5. The care plan is reviewed regularly by multidisciplinary teams in a primary care setting.
6. Clear safeguarding and escalation protocols are put in place to ensure that medical attention is delivered effectively and in a timely way when needed.

From 'Personalised Integrated Care', Age UK website, <https://www.ageuk.org.uk/our-impact/programmes/integrated-care/>

### The Age UK Personalised Integrated Care model



### How the Croydon PIC Service is Delivered

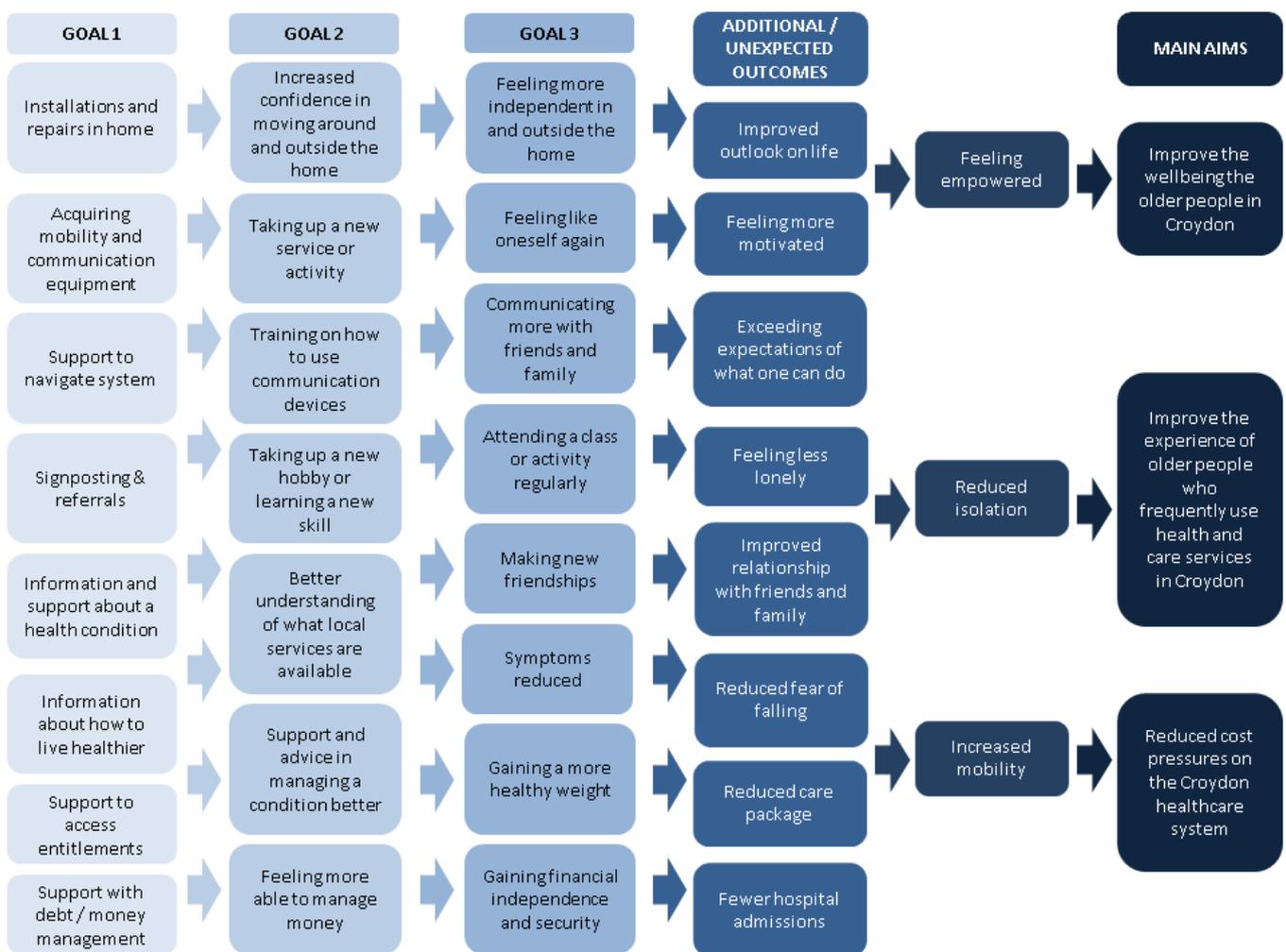
In Croydon, the PIC Service is comprised of 18 Personal Independence Coordinators (including 4 Team leaders) and 2 support workers, working across the 6 localities/ GP networks in Croydon. This comprises 3 locality-based teams (2 networks per team), and one cross-Borough community-based/ backup team. They are managed by the Service Manager, who report to the Programmes Director,

and in turn to the CEO and Board of Trustees. Reporting to commissioner on achievements against KPIs, Outcomes, Quality and Process.

PICs attend and take referrals from 49 GP Huddles (one per practice), and participate in wider locality-based Multi-Disciplinary Teams across the Borough. The original cohort was limited to over 65s with a minimum of two non-elective hospital admissions within the last year, and two long term conditions. However, the age scope of the service has increased over time, as the value of the PIC service to people outside of this age range was recognised. It was extended first to people over the age of 50, and most recently, to a pilot service working with anyone over the age of 18, which concluded in July 2021.

**Theory of Change**

AUKC developed a theory of change for the service to clarify the benefits that the service is intended to have, and how this will lead to positive outcomes, meeting the intended aims of the service.



To aid understanding, a narrative overview of the service and how it is currently delivered is outlined below, including some observations from professionals on the intentions behind each stage.

**Referrals and huddles**

GPs and other members of the huddle teams are able to refer people to the service whom they identify as at risk of hospital admission, or who are otherwise considered at risk, or frail and

vulnerable. In particular, referrals tend to focus on older people who have issues with mobility, social isolation, emotional needs, financial management and support, their ability to self-manage their conditions, their ability to cope with day to day living at home (in their own home), and with carer support. There is flexibility however, and any adult who gives sufficient cause for concern for a member of the GP huddle core team can be referred.

“The coordinating role with other services is very helpful. Very often there are really clear opportunities to utilize the PIC service [...]. For example, someone may be struggling to leave the house, and isolation may have become a big issue. They are also able to help people access a wide range of other services - when GPs and health professionals wouldn't really be able to. At the same time, PICs sometimes help bridge the gaps within the NHS – they give practical support for people to attend appointments, chasing up referrals, and so on. In many ways they act like an alternative to a relative or a friendly neighbour. Because a lot of people don't really have one of those.” (Local GP)

### Guided Conversations and goal-setting

PICs, and the huddle teams, consider a range of factors, ranging from the very practical, to the more emotional and social. The boundaries between these are often blurred: very practical concerns have a negative impact on older people's day to day living conditions, which then have a severe negative effect on their mental health and physical health. One GP described the battle as being to 'break the cycle of *stuff* causing more *stuff*'.

'Lack of those issues being sorted out makes or breaks issues with medical complexity. If people aren't managing, and it is not sorted out, then they end up in hospital and in institutional care.'

- Local GP

For this reason, the 'Guided Conversation' takes a holistic approach to identifying clients' needs. The initial conversation includes setting baselines using the Short Warwick Edinburgh Mental Wellbeing scale (SWEMWBS), which allows exploration of some of the mental health and broader quality of life issues that older people may be experiencing.

From this Guided Conversation, a personal care plan is developed. This includes setting specific goals that the PIC will help the older person work towards over the course of between 8 and 16 weeks. The goals are developed with the older person themselves, to ensure that they are things that they fully 'buy in to', and that they are truly driven by what will make the biggest difference to them - rather than by any standardised interventions that may be selected according to a pre-existing 'offer' or intervention. Goals are also developed with eventual independence in mind. The length of the intervention is decided by use of a complexity tool, which considers both the complexity (not just number) of goals, but also any barriers or challenges which may have an effect on the amount of time needed to make a difference. There is no specific number of allocated hours to work with each individual, which allows for additional flexibility to achieve goals.

### Active problem-solving and advocacy

The PIC will then continue to build a relationship with the older person, helping the client to achieve the goals identified. This involves going beyond a purely 'signposting' model, with a PIC taking a

proactive, advocacy, and practical role, and often acting as a case manager for clients, taking responsibility for the coordination of the individual's care as part of the Multi-Disciplinary Team. The PIC will also act as an advocate within the health and social care system and help clients navigate the sometimes highly complex systems. Acting as a single point of contact is intended to avoid the overwhelm and confusion for clients of a large number of separate referrals, interventions, professionals, and organisations.

#### Enabling independence - with appropriate support

By the end of the intervention, the goal is that older people will be more independent, and more able to manage their own health care needs, with appropriate support and services around them. (In interviews, one GP described this as becoming 'independent citizens of their own lives'.) As part of that, PICs support clients to build (and sometimes rebuild) relationships with important providers of support (for example healthcare professionals, or sometimes friends and family, or the voluntary sector).

'For example, going to the GP with them. What you're doing is promoting independence by helping them make the first step to connect with a GP, or someone at the GP practice, helping them build an initial relationship, so that when they go there in future, they feel more able to do it on their own. When you go initially and people lack confidence, or forget things, you're able to prompt them, you're able to help them remember things that they need to remember to tell the GP, and you can advocate for them. GPs see that it actually helps them to do their job better. It means that things aren't missed.'

- AUKC PIC

At the same time, by helping the client 'move on' with some of the blockages they are facing, they will be able to manage better in future once they are 'in a better place'. At the end of the intervention period, the SWEMWBS assessment is undertaken again, and progress against goals is measured. Clients can be referred back to the service in the future if they need it; however, to date Age UK figures show this has only been necessary in around 24% of cases.



## The Impact of the Service<sup>9</sup>

### Key outputs

- 1,127 clients accessed the service in the last year, with 909 referrals within the period<sup>10</sup>
- 1,382 goals were set in the last year (Aug – Sept 20-21)
- 18,507 contacts took place<sup>11</sup>
- 671 guided conversations took place<sup>12</sup>

### Key outcomes

- 98% of clients improved their mental wellbeing in the last year (94% over the last 3 years)
- 99.6% of clients achieved at least one of their wellbeing goals (over the last year)
- 83% of all wellbeing goals were achieved (in the last year)

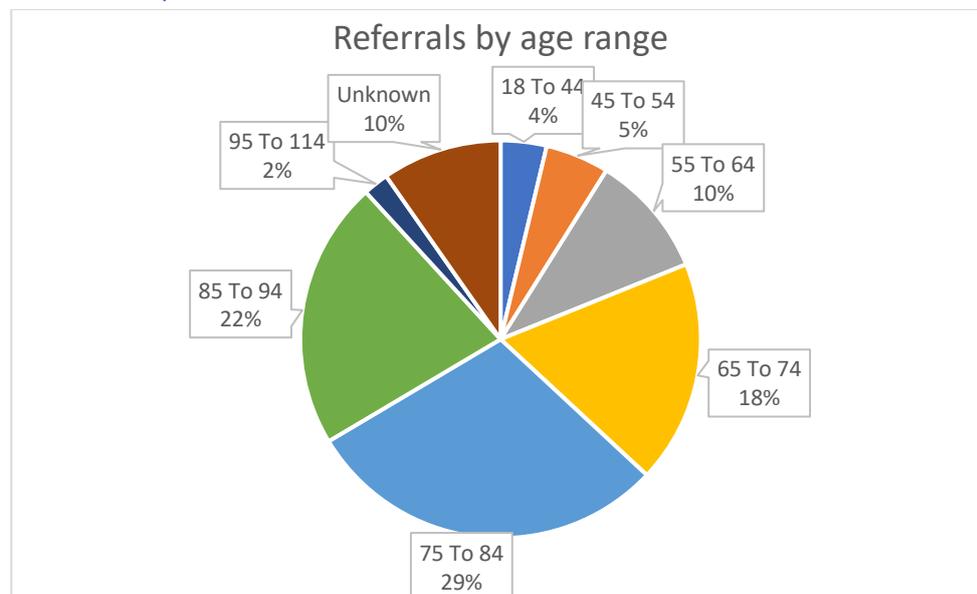
### Client satisfaction

99% of clients say they would recommend the service to friends and family (over the last three years), and 100% in the last year.

### About PIC Clients

The following graphs and figures are based on data for September 2020 - August 2021, the period for which the fullest data is available. Data and graphs were provided by Age UK Croydon staff.

### Who are they?



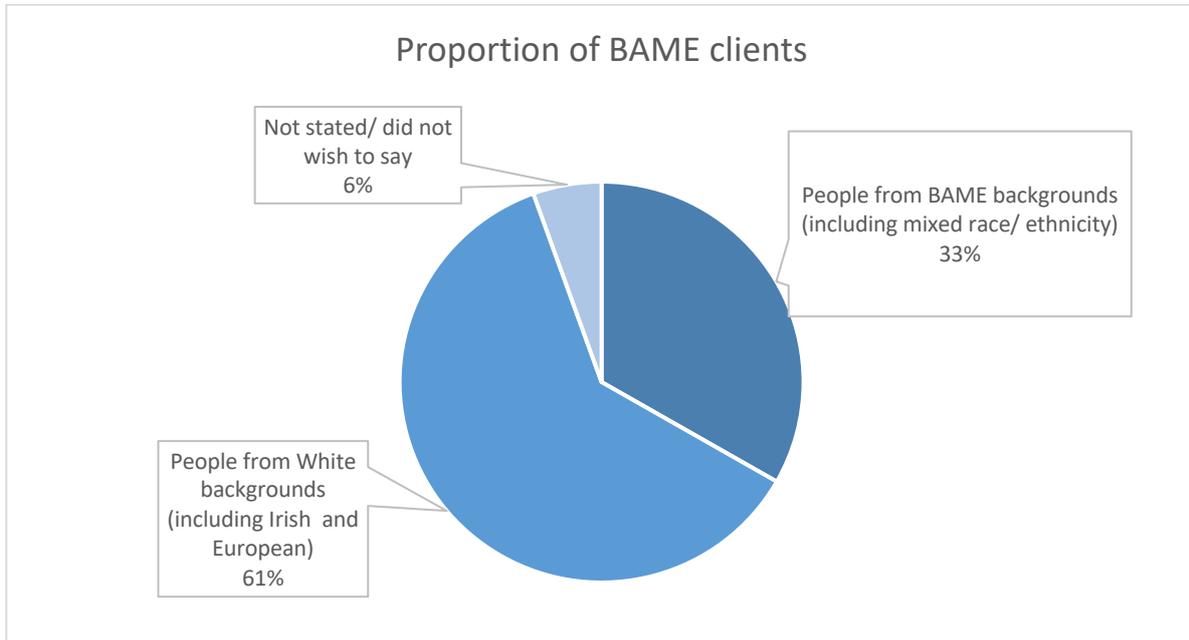
<sup>9</sup> All figures provided by Age UK Croydon.

<sup>10</sup> The number of Organisations and People who have either been referred or who have been referred earlier but who have had a contact within the time period requested.

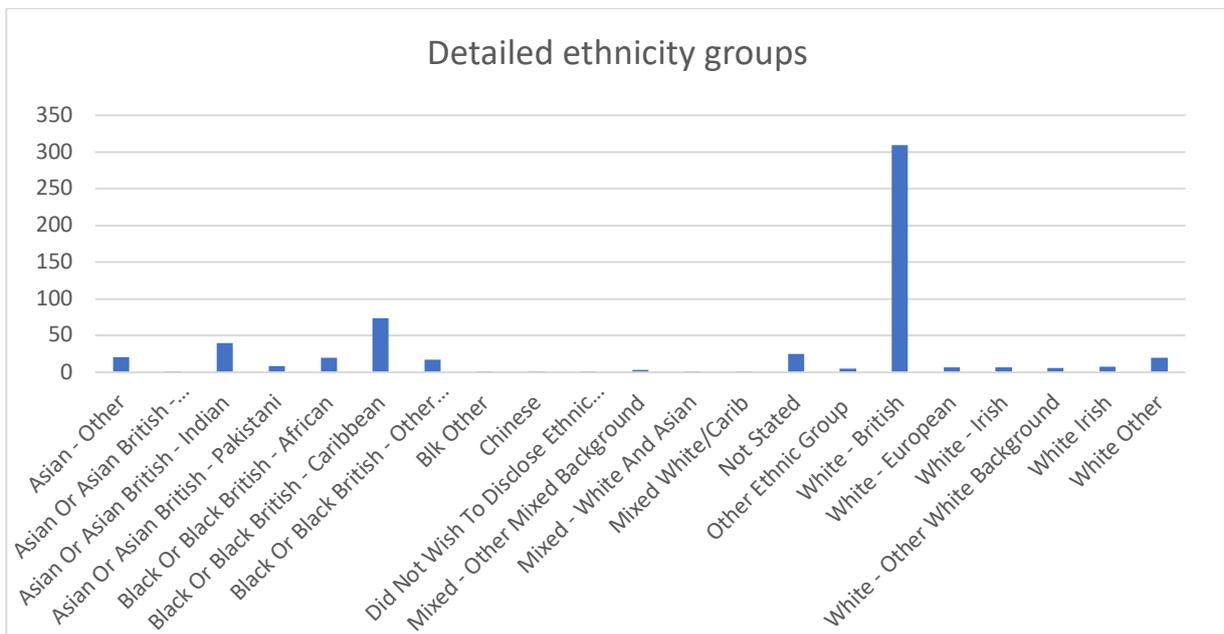
<sup>11</sup> Numbers of contacts with, or on behalf of clients, by clients themselves or organisations representing them - this includes the first Referral contact and any subsequent contacts for that Referral in the requested date range. Contacts undertaken in Home-Support type services or clubs and groups are not included.

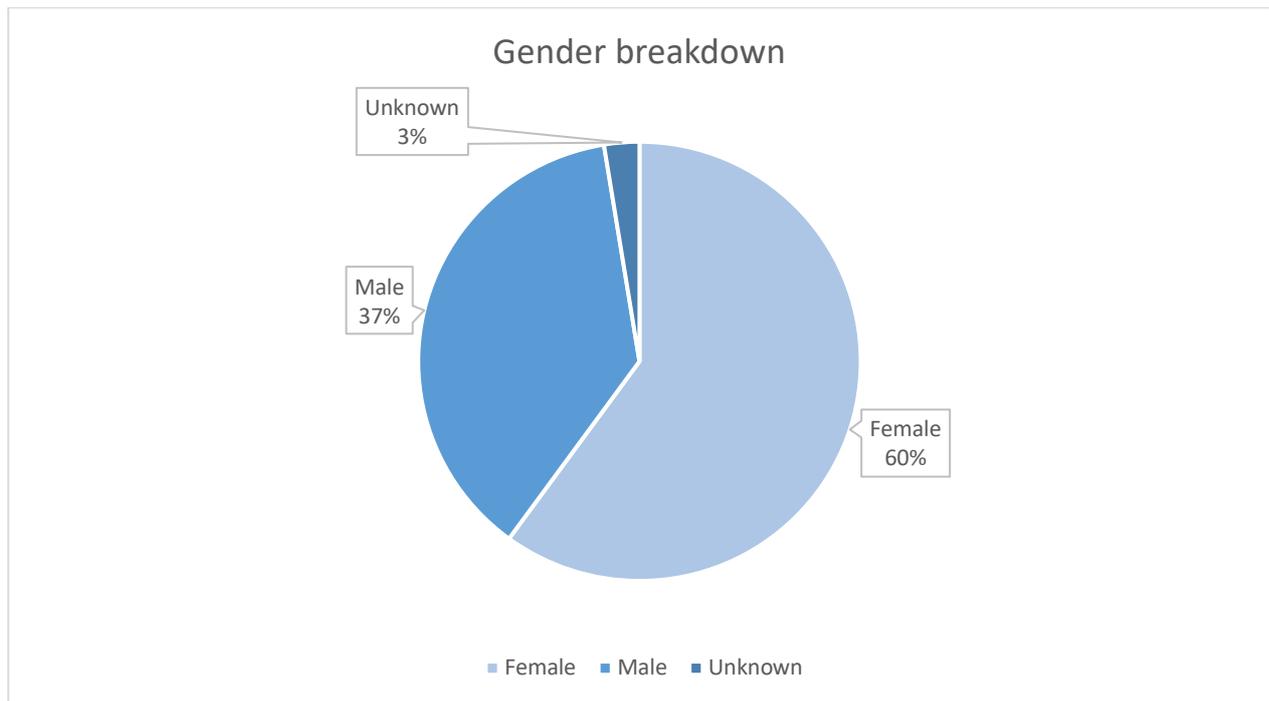
<sup>12</sup> This number excludes people who had guided conversations prior to the period, or who had yet to receive guided conversations, while the number of people using the service includes those who were receiving the service but had already had their initial guided conversation.

There is a fairly even spread of people using the service between the ages of 65 and 94. Lower numbers in the younger regions may reflect a fewer people with need, It would be interesting to consider whether this represents lower levels of need in that population group, or other factors.



There is a slightly lower proportion of BAME clients using the service compared to the BAME population breakdown in Croydon (33% against Croydon’s 44.1%). However, further investigation to identify whether this represents a different breakdown of ethnicity in the older population, or other demographic factors (eg. geographical location, in a Borough where relative spread of ethnicity is very different depending on location) would be useful. Another issue PICs have noted is that some people do not wish to discuss or record their ethnic background – in some cases this is due to anxiety about immigration status, or a fear that they may be discriminated against. Age UK Croydon has prioritised looking more closely at their work in terms of engagement and effectiveness for people from BAME backgrounds in the coming year, with data as one key starting point.



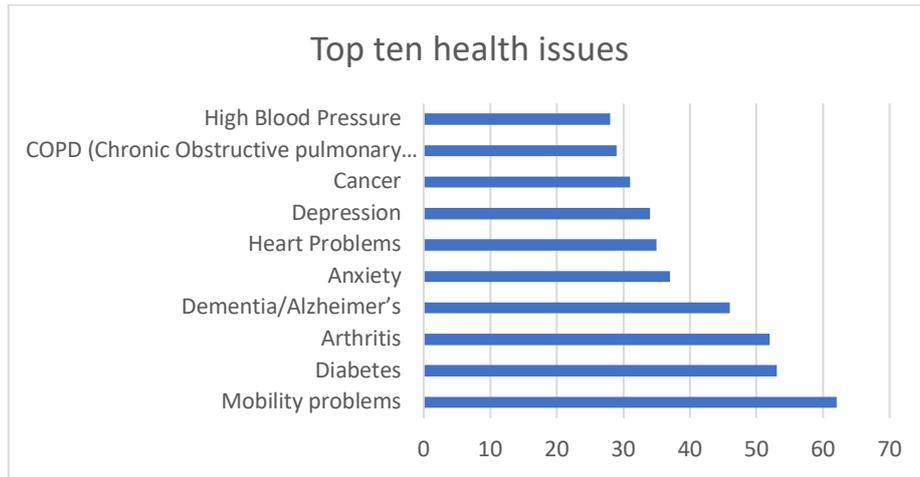


Gender gaps here may to some extent represent disparities in life expectancy – however, there is also often an issue with older men asking for and receiving support for their health and social care needs. Further investigation may be useful here to ensure that older men are being reached as and supported with equity.

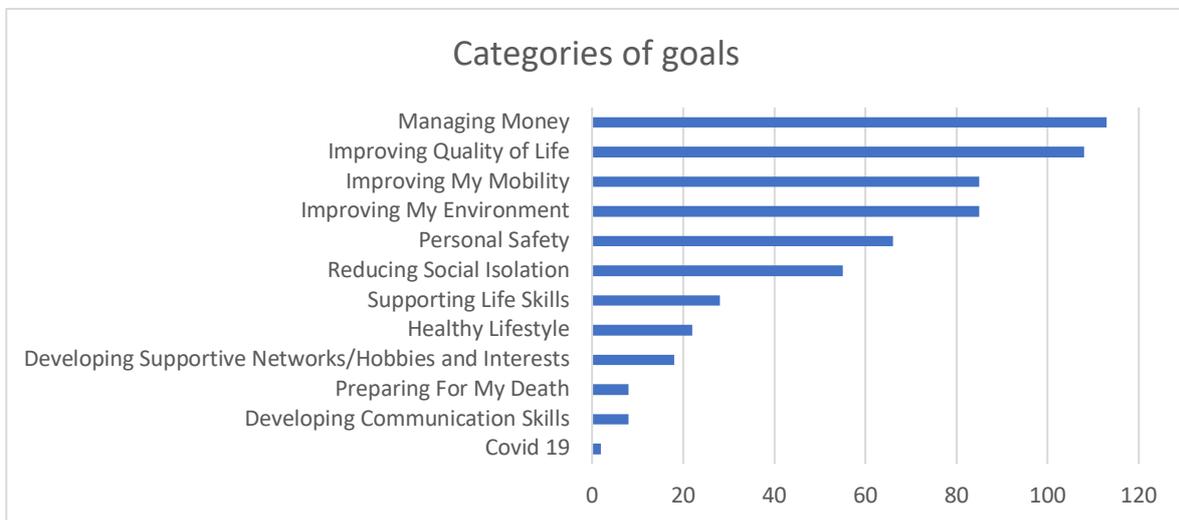
#### What did they need?

The graph below shows the most common health issues for clients who were referred to the service. This does not necessarily reflect the reasons that they were referred, which are for a range of non-health related issues. At the same time, mobility problems feature heavily, as do mood disorders. If we were to combine the two mood disorders in the data (depression and anxiety), the new category dwarfs all other.<sup>13</sup>

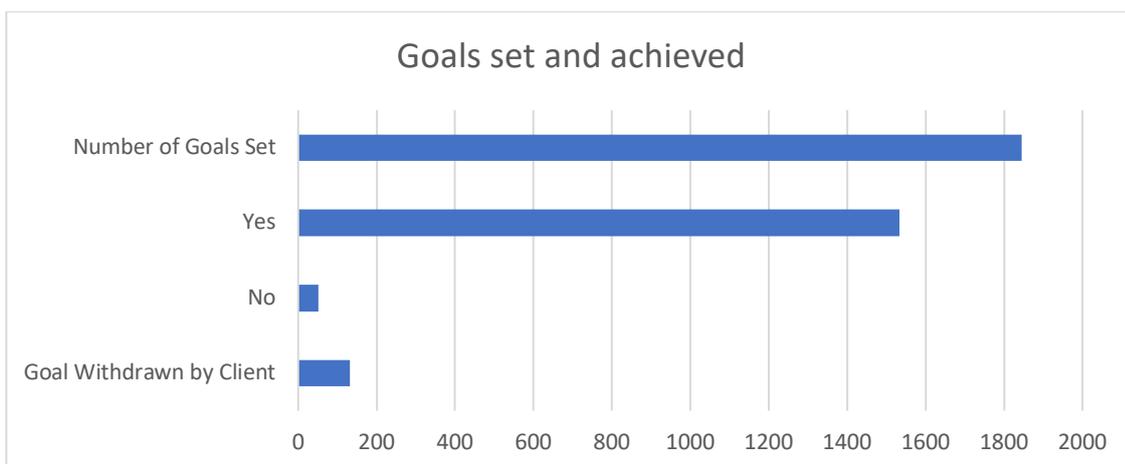
<sup>13</sup> In terms of future gathering of data, some further consideration could be put into to what extent these are the best categories to record and report on, since they do not necessarily map to outcomes.



Once clients are referred, they are invited to set their own health goals. These sometimes map to the original reasons that they are referred to the service, but at other times can diverge.<sup>14</sup>



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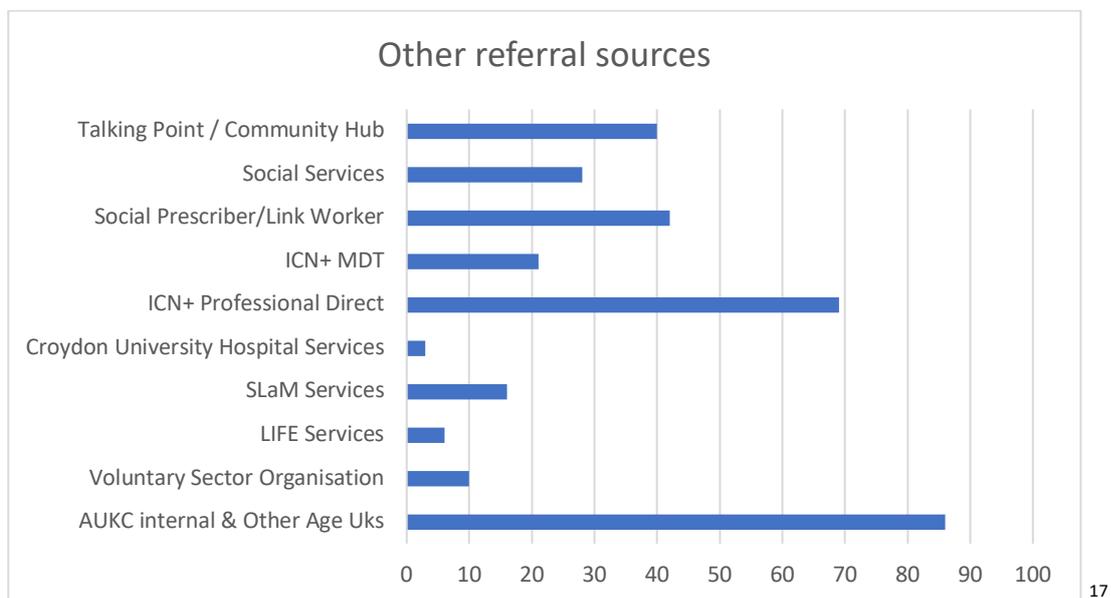
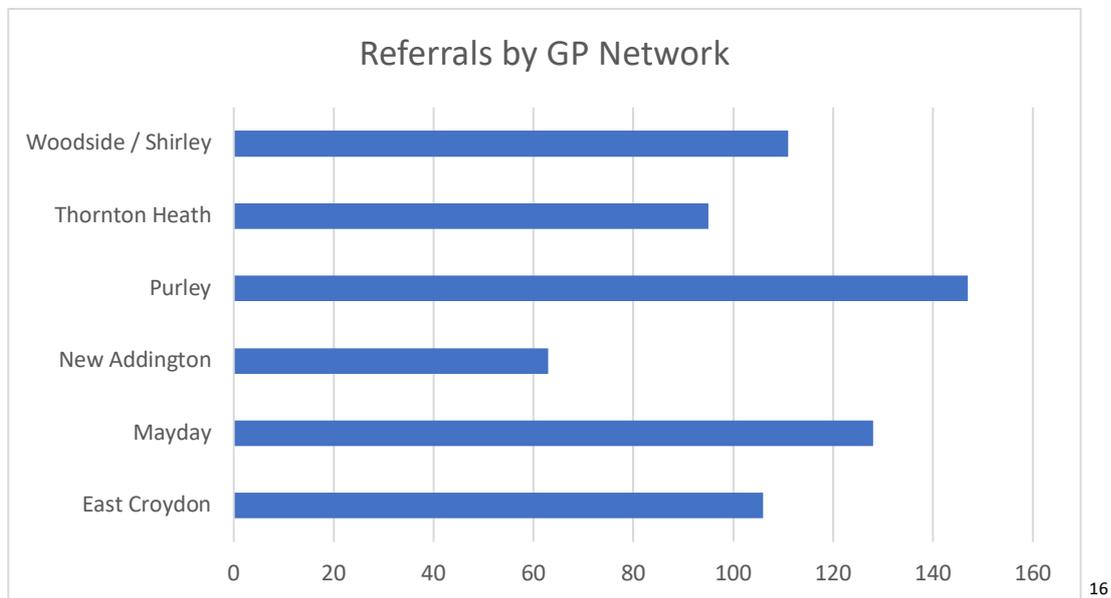


<sup>14</sup> It may be worth considering whether the 'improving my quality of life' category is too general given the relative specificity of others in the list.

<sup>15</sup> Based on 597 records. Some goals were not assigned categories in the original data.

### Where were they from?

Referrals for the service were initially drawn from GP practices and GP huddles. However, in line with the developing ICN+ model, referrals have been opened up to a wider set of community referral partners. Other ICN professionals, and elsewhere in Age UK Croydon (and some other AUKC branches) have formed the largest sources to date.



<sup>16</sup> Total of 650 referrals, excluding records where this information was not recorded.

<sup>17</sup> Total of 321 referrals, excluding records where this information was not recorded.

## Meeting the Outcomes

“I felt understood. Someone had the patience to listen and hear what I was saying.”

- PIC Person, Friends and Family Survey

### The service improved wellbeing

According to the Short Warwick Edinburgh Mental Wellbeing Score, 94% of clients improved their mental wellbeing over the last 3 years, with 98% doing so in the last year. The average

(mean) increase in the last year, at the end of the intervention was 3.87 points. This shows a meaningful improvement using a nationally recognised standard, compared to an externally verified baseline. 78% maintained their mental wellbeing or improved further in the 2 months after the end of the intervention, with 44% improving up to 4 further points. A further 6% improved up to 6 points, and 2% continued to improve by over 10 points.

In terms of qualitative data, clients spoke of the substantial difference to their mental health that the service had made through a positive, listening and supportive relationship with the PIC, the improvements in their lives that practical help had produced, and a renewed ability to ‘cope’, leading them to feel more independent.

‘In many ways they act like an alternative to a relative or a friendly neighbour, for the people who don't have one of those.’

- Local GP, interview

‘In some ways we do, but we're a lot more than that. There are all sorts of thing we know, and things we can do that a family member never could. Also, we have a lot more time than a neighbour or even family member.’

- AUKC PIC, focus group

Health professionals noted the value of improvements in mental wellbeing on their wider dealing with patients, and their ability to help patients engage with their conditions. They also thought that the attention paid to the needs, desires, and goals of the patients themselves helped ensure that the service, and the GP relationship, were able to have the strongest possible impact. They thought that attention to the subjective experience of the patients was central to the service's success in making a difference to mental (and to some extent, physical) wellbeing. Patients frequently referred to the fact that they were ‘listened to’, and in particular, that they felt the PICs were ‘non-judgmental’ and open.

Patient feedback on the friends and family survey showed a strong recurring theme of increased independence and ability to ‘cope’, and an ability to ‘get back on track’ again, showing they were more able to engage with their own needs, and felt a sense of enhanced agency.

Practical support had very substantial positive impacts, from patients who received substantial amounts of welfare payments, to those who were able to become mobile again after protracted periods of being housebound, to those who rekindled relationships with family members or other forms of social support, due to the support of their PIC.

### People reported a better experience of using NHS services

98% of people who used the service over the last 3 years would recommend it to their friends and family, and 100% of people in the last year.

Health professionals were clear about the benefits of patients having one single source of support, which could help manage multiple, often confusing referrals, from various NHS departments and beyond. Patients also spoke of the benefit of having a more proactive approach to referrals and various treatments within the NHS – whereas in most situations, there is a total reliance on the patient proactively seeking out a way through complex systems, the PICs were able to actively chase referrals, and actively keep patients updated. Several patients noted that the fact PICs ‘follow through’ and actively communicate with clients contrasted with their previous experiences.<sup>18</sup> Meanwhile, health professionals appreciated the fact that PICs were willing to challenge the system, and bring a patient voice that was sometimes missing – as well as to advocate strongly for individual clients in their coordinating role.

“You thought about how to help me. You are one of the best things that has happened to me and you've given me hope. I'm an expert with my taxicard now - I can go to my appointments and not have to worry about the cost!”

“You helped me with everything & I couldn't have achieved it on my own and its put my mind at rest (emails from phone, tv licence, council tax, rent, benefits, tenancy were all worrying me!”

“I feel that I've been supported in every way.”

PIC Clients, Friends and Family Survey

“I felt I'd been left to just get on with it but now feel with your help (and GPs) more supported.”

“You know your stuff and you're the only person who actually does anything they say they are going to!”

“You contact me and keep in touch.”

“At least someone is ringing me and asking how I am rather than leaving me to get on with it like some of the other do.”

- PIC Clients, Friends and Family Survey

### Professionals believe the service reduces cost pressures on the NHS

All patient-facing health professionals interviewed said they could point to examples of patients attending less frequently – or more appropriately – due to interventions by the PIC service, and PICs themselves thought this was the case. GP surgeries and other health professionals felt that the service was likely to make their work more efficient, and to save them time in the long run.

<sup>18</sup> Although it was not specified whether they were referring solely to NHS services.

On reducing attendances at GP surgeries or hospitals:

‘The question is why are they not attending? Where attendances were nonmedical, that is where they have reduced. And that is what the PICs have helped stop. It has reduced the presentation of non-medical need.’

- Local GP

One of the driving factors in the PIC service, and the wider ICN(+) model of care, is to reduce cost pressures on the NHS. Moving interventions ‘upstream’ is a key part of this. All professionals involved in this evaluation were quite clear that the goal is not simply to ‘stop people using services’, but to ensure they use the right service, at the right stage, at the right time.

All professionals were clear that reducing cost pressures was only one goal for this service and the ICN as a whole - and that the most important was improving patient care. Several thought that the financial benefits of the service might be more visible in the primary care arena rather than in secondary or emergency care – which was part of the reason that some were keen that the service should expand interventions even further ‘upstream’ with outreach.<sup>19</sup> There was also consensus that any savings would likely be incremental, visible only at scale (possibly at a scale much larger than the PIC service) and take many years to be seen, if indeed they could be measured meaningfully. Hospital data on emergency admissions and A&E attendances showed no clear trends - but this had been predicted by several health professionals who thought the differences made would be too complex and multifaceted to be measured in this way. (See Outcomes and Evaluation section later in this document).

## Feedback on the PIC Service

Stakeholders and clients were asked to discuss their perceptions of the service. Below we discuss a list of the most common themes.

‘The PIC service is very valuable – hugely so. Before that, patients would've got stuck – they would never have been able to achieve better health. Nobody could fix the bits in between. But PIC's can do that. We need to celebrate how much we've achieved – and how far its development has gone compared to other places.

- Pharmacist

## Health and Social Care Professionals

There was unanimous agreement amongst health professionals interviewed that the service is extremely valuable, further confirming the findings of the previous evaluation. They particularly appreciated the contribution that PICs made to issues with mobility, which in turn reduces social isolation, with connecting patients to social networks, and help with issues such as accessing

<sup>19</sup> Gathering patient feedback on this is difficult – alongside recall bias (can patients remember how often they have attended?), one of the strengths of the PIC service is that patients do not necessarily associate the service with the NHS (partly because it is so wide-ranging), and therefore will not necessarily ascribe changes in attendance, or even to their physical health, as being the primary positive outcome of their experience.

financial and housing support, and care packages. At the same time, health professionals appreciated the attention paid to the subjective experience of patients – that is, the focus on what was most important to *them* – whether that was help accessing benefits or medical appointments, or going to a garden centre, or getting their kitchen cleaned.

#### Dealing with non-medical needs that have impact on the medical

There was strong consensus that the service had a very strong impact on the wellbeing of patients, by significantly raising their quality of life. All thought that helping improve a patient's general living standards had a significant positive impact on their physical and mental health, and all said they had seen this 'in action' many times.

It was felt that the PIC Service provides a whole new way of looking at health problems. As one GP put it, 'It's given us an outlet that we never had before,' allowing professionals to think much more broadly about 'what would make a difference to people's quality of life.' The service also seemed to go some way to removing a sense of powerlessness when presented with non-medical issues which would nonetheless impact patients' medical outcomes. This was seen as especially helpful for patients with long term conditions.

'I've found myself thinking, is there anything more that we can do? [...] There's nothing more medically that we can do. And [the patient] may not get a care package. So what can you do? The PICs give you *something you can actually do.*'

As another GP said,

'Lack of those issues being sorted out makes or breaks issues with medical complexity. If people aren't managing, and it is not sorted out, then they end up in hospital and in institutional care.'

#### The Community Pharmacist's experience

A pharmacist visited a man who was living alone with dementia and had problems with his medication. When she went to visit the man in his home, she had noticed problems like the fact that he had no food in the fridge. The PIC was able to come along and help him get food, and deal with other problems in his day to day life. If those hadn't been dealt with, thinking about his medication would only have been one of his many problems, and probably low on his list of priorities.

Other professionals saw the PIC service as an exemplar, and in some ways, a driver of cultural change in the NHS.

'PICs are driving culture change - they are people who have the right mindset. This could be exploited more, and the PIC could be the centre in some ways of the culture change that the ICN+ requires. Their role could be partly as people who are changing the way the NHS considers the person-centred nature of care. We need to extract learning from what the PICs do – their advocacy, and patient centeredness – and import this to the NHS to produce culture change.'

- Senior Consultant

In general, there was consensus that the person-centred approach which starts with what the person needs, rather than being led by the 'list of potential interventions' was vital: this is no longer 'referral by task [...where..] each need was given a separate referral. Clearly that was not going to work.' (GP)

#### Flexible and holistic

'They are not constrained by contractual obligations to provide a very clearly defined service. They have the flexibility to sort what needs sorting.'

- Lead Pharmacist

The flexibility of the role was seen as a key strength. One interviewee noted that 'flexibility is baked-in' because the contract grew from Age UK's design of the PIC model, which allows people to 'respond in an agile way, but also set reasonable boundaries'. PICs, and the service as a whole, benefit from 'Flexibility and willingness to just get involved.' (GP)

'They have a lot of flexibility to do whatever the patient needs, which is not common in the NHS.' (Pharmacist)

'They're flexible and always find a solution' (ICN+ lead)

'They have the flexibility to just sort what needs sorting.' (GP)

#### Organisation, governance, and management

Other particular strengths mentioned included good local management by Age UK Croydon, and strong team management. It was noted that when there were team changes, these were coped with well. It was noted that this makes the service trustworthy, even for health professionals who have little experience of working with the voluntary sector. The focus groups run with PICs, demonstrated very close supervision and case management, at each level, and close attention to onboarding and training, alongside experienced PICs being given the flexibility required to make decisions and manage their own time. This is clearly a 'tight ship'.

#### Advocacy

Another area of consensus was the high value of PICs' advocacy for better, more timely, patient care - their willingness to 'chase' the system and challenge where necessary was appreciated by professionals as much as patients. Some thought that that the PICs provided a much better sense of a patient voice which often felt like it was missing in clinical work.

#### A Gateway to the wider VCS

Interviewees all saw the value of the PICs acting as an advocate for, and a gateway to, the VCS within primary care. The service provided some continuity and 'local intelligence of a shifting network,' whose diversity offers an alternative to people 'getting referred around standardised interventions

in the NHS.’ Being an integral part of that network gave them special access, and a much stronger knowledge than could be held within the NHS itself.

Some suggested that the decentred and constantly changing nature of the VCS could be difficult for health professionals to work with, in strong contrast to the more standardised nature of the NHS. As one professional noted, ‘If I go to a hospital in another part of the country, I can be a consultant there straightaway, because I know how a hospital works. That is not necessarily the case with the voluntary sector.’

Perhaps for this reason, it was thought that the service went some way to reducing any anxiety about the lack of standardization in the voluntary sector, and the fact that NHS professionals sometimes feel that they ‘don’t know what they’re getting’ when they refer. Having a trusted partner like the PIC Service, that liaises with the VCS and works closely within the primary care framework goes a long way to reducing this anxiety.

#### Time-scales and trust

It was widely felt that the amount of time that the PIC service was able to give to patients was one of the most important factors in its success. This allowed PICs time to build trust – which could then be transferred to professionals, for example by attending medical appointments as an advocate, or to help patients remember or explain further. Health professionals felt this enabled them to be much more effective when dealing with patients and planning their care. PICs and health professionals were in strong agreement on this.

It was also noted that, in general, many patients were more comfortable with dealing with the voluntary sector than with statutory services at the outset – some felt there was a risk in involving the ‘authorities’ in their lives. Some patients had had very negative experiences with statutory services which they felt had not listened to their needs. The PIC service improved their experience of using health and social care services because they felt that they were being listened to, and their own preferences taken into account.

#### Home visits

Health professionals, especially GP surgery staff, found it helpful that PICs were able to act as their ‘eyes and ears’ by visiting patients in their homes. Importantly, they were also able to act upon the non-medical issues they discovered, in contrast with other professionals who visited homes but were limited to very specific interventions and support they could provide.

#### Improving the Service

Professionals were also asked to suggest areas for improvement, or future, development.

##### *Dealing with serious mental illness*

Health professionals recognised that sometimes referrals had been made to PICs that were inappropriate – especially those with serious mental illness. Changing this was seen as a matter of more responsible referring from external professionals, although it was thought that more training could also help. Most important was the commissioning of the Mental Health PIC Service set up by Mind in Croydon in partnership with Croydon BAME Forum after the model of Age UK Croydon. Professionals hope that this will bring people who have more

experience of dealing with those conditions on board, and allow referrals to be more appropriately dealt with. The impact that this has made has yet to be determined.

#### *More training, and pathways in partnership*

Several suggested more training, developed in partnership with PICs, to be rolled out across the ICN+ and NHS, and more care pathways co-developed with the service.

#### *A whole-population approach*

Moving to a whole population approach, and expanding the service to all ages was seen as something which could be highly effective. For example, the level of need for young people was suggested both by front-line and commissioning professionals. The fact that the service had been expanded to the Mental Health PIC service run by Mind Croydon and Croydon BAME Forum was seen as potentially very positive.

#### *Moving further upstream*

GPs in particular wanted to look at expanding the intervention further 'upstream', and perhaps integrating an element of outreach and active search for clients.

#### *Greater integration with social care and health*

There was enthusiasm for further integration between the PIC service and statutory services, with the forthcoming co-location seen as a big step forward. There was some divergence however between those who thought that bringing services like the PIC service almost 'inside' the statutory sector (eg. working within social services teams) would increase their impact, and those who felt that their position outside those statutory systems actually increased their effectiveness. This raised questions about the idea of additional NHS coordinators – 'Care Coordinators' who it was thought may duplicate the work of the PIC service, but also find they are not sufficiently networked, and do not have the level of flexibility and independence that the voluntary sector can have. Others wanted to see the advocacy and challenge role of the PICs given greater status as it relates to representing the voice of the patient.

## Voluntary Sector Professionals

### *Relationship to Social Prescribing and similar community-based roles*

A theme that was raised by professionals in the ICN and outside the healthcare sector, was uncertainty about how the PIC Service related to some other roles in the Croydon network, and how/ whether it was unique. Distinctions between Community Builders, Social Prescribers, and other kinds of coordinators felt blurred to some. It was noted by some from the VCS that a holistic, person-centred approach is standard practice for many local charities (who include elements of case management, IAG, coordination, advocacy, and emotional support) and for several other statutory funded roles in the sector. VCS leaders were at pains to point out that there were many VCS organisations, and roles, contributing in similar ways, and all are equally important. It was thought by some that while, on paper, they seem completely distinct, there is a lot more overlap than you would expect in practice - 'however, that's not necessarily a bad thing' (Local Authority manager).

This may also speak of an understandable concern that, in a tight funding climate, PICs should not be the only point of statutory investment in the sector – not least, the PIC service relies on many other VCS projects and services to achieve its work.

Health professionals seemed to have a stronger sense of each service’s distinctness, even while they understood the overlap.

“Once you’re inside the system it's very clear who is best placed to do what, and which patient will benefit most from which service.” (Local GP)

“What we need to do is move to a system where colleagues can just do the best job. There is some overlap between PICs and social prescribers, but there is also a great deal of non-overlap. If there is overlap on who does which thing, that's fine, then you decide. But if not...” (Local GP)

Overall, while there is a clear understanding of the PICs’ distinctiveness for the NHS staff we spoke to, a clearer understanding *outside* NHS primary care is also likely to be important for its sustainability, and its ongoing effectiveness, especially as the ICN+ network expands. Overall, there was agreement across all of the professionals that all of the services were useful, remained distinctive, and were much needed, even while there was some (beneficial) overlap.<sup>20</sup>

### Social Services

Social services were also asked for feedback on the service.<sup>21</sup> Social workers particularly appreciated the work PICs do with practical tasks, such as decluttering and cleaning accommodation, particularly by working with the client themselves on the issue. They also noted the value of the emotional support that was provided by PICs, especially with clients who have been difficult to engage. As with colleagues in the NHS, the sense of collaboration which begins in huddles, and allows the dividing up of tasks as well as joint visits, was seen as very helpful.

Other interesting points included the fact that PICs were able to make a difference to those around the specific client they shared Social Services. The fact that they were able to help rehome a client’s son, which then had a substantial impact on the client themselves, again demonstrates the importance of flexibility and ability to think beyond the immediate. This was unlikely to be something that Social Services would be able to solve unless the son was also a client. Finally, as with the NHS professionals and clients, the knowledge of the wider voluntary sector was seen as valuable.

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<sup>20</sup> It should also be noted that in the friends and family feedback, little reference to specifically arranging social activities was made, which suggests that, much as this often occurs and is appreciated, patients themselves do not see this as a primary purpose of the PIC service. Far more attention in patient feedback was paid to the practical support, and the personal connection over a long period of time that the service offered. Part of the disparity here may be that clients often do not see being linked up with friends or groups to reduce their loneliness as part of a ‘service,’ and that they will inevitably be more aware of very practical changes (eg a new wheelchair, or improved benefits payments).

<sup>21</sup> Social services staff were not available for one to one interview during the research, likely due to heavy workload. Instead, as a sample, team members from the North East Locality were asked for feedback, which are quoted here.

“The Personal Independence Coordinators (PICs) attend our weekly Peer Forums and provide valuable input, advice and take direct referrals, which aid in achieving positive outcomes for Croydon clients. They support with signposting and have an excellent knowledge base of the wider voluntary sector in Croydon” (Social Services Manager)

“I worked with the PIC service on two long-term cases. Josephine supported with de-cluttering and supported my client emotionally to give her confidence to sort out wanted/unwanted possessions. I also worked with Jessica, who supported my client’s Son to be rehomed, which improved the wellbeing and environment of my clients”. (Health and Wellbeing officer)

“I worked with Josephine on a difficult to engage self-neglect client. We were able to collaborate at the huddle, this aided communication and dividing up tasks. Josephine supported him to clean their environment, set up a phone and supported him to gain confidence going out. Josephine was flexible to accommodate their needs which resulted in a positive outcome. He is now going out independently into the community”. (Social Worker)

“Mitzi has done some excellent housing advocacy through the huddle. The PIC service are good at working preventatively with clients”. (Experienced Social Worker)

“PICs have supported my clients with completing attendance allowance forms, practical and social activities. I have undertaken joint visits with the PICS using their in-house projects such as the Personal Safety Project to support clients”. (Experienced Social Worker)

In terms of future work, it was noted that there could sometimes be questions about whether clients with cognitive impairments were able to effectively set goals. Further conversations about this approach between social workers and the PIC service, and particularly about how they approach this consistently across huddles, could be helpful.

## The Client Viewpoint

There was overwhelmingly positive feedback for the service from users in the NHS Friends and Family survey. Key themes are outlined below.<sup>22</sup>

### A truly transformative service for clients

Clients often described sense of despair and hopelessness giving way to a new state of hope and change to their lives. A narrative of substantial or total recovery/ transformation is common in the Friends and Family Service feedback.

“I was down a very deep hole and couldn’t see the way out but now I am near the top – you’ve made a huge difference to my life this year. I can’t thank you enough.”

“The whole Age UK Croydon team helped me out a lot. I wouldn't be here without your support. I was surprised by how much AUKC does. I have been lifted out of a deep, dark well

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<sup>22</sup> Quotations here are either from transcriptions of calls made to clients by Age UK Croydon staff, or directly from written responses via email or on paper.

and into the light. Hearing a voice at the end of the phone brought so much comfort to me during a dark time.”

“Life changing service. I was down and out when the lady from Age UK started supported me.”

### Independence through encouragement

Improvements with confidence and 'coping' were often mentioned - and this support particularly helped people build greater independence and ability to self-manage. Stopping patients 'beating themselves up' or encouraging them to overcome problems was a common theme, alongside a sense of renewed purpose and forward momentum. A renewed ability to 'cope' was common.

“Immensely pleased. I feel I know where I'm going now!”

“I feel that you've helped me so much along the line - it's given me hope. I feel much stronger in my mind now.”

“The PIC service has given me so much more confidence and done so much for me.”

“Without hesitation I would be extremely likely to recommend the service. You have helped me so much and I found it really supportive. When I saw it was you calling it made me really happy. It's got me out of the ditch and back on the right path. It's given me clarity and I couldn't have done it on my own.”

“You kept me going when I couldn't be bothered anymore. You supported me through a hard time and motivated me to keep going.”

“The PIC was really helpful when we were not sure what we would need to move on.”

“You've helped me to not beat myself up so much and to focus on moving forwards.”

‘I felt supported and encouraged to sort through issues with support.’

### Taking a proactive approach to care

PICs take a much more active approach to problem solving, whether regarding healthcare referrals or other practical tasks. Chasing test results, chasing taxi cards, following up on care packages, were all things that people felt unable to do themselves at the outset – and the approach by statutory services was characterised as almost always passive. The confusion, distress, and sense of overwhelm that patients often felt when dealing with bureaucracy across statutory services was something that PICs were able to help reduce, at least until clients were able to begin engaging with the issues again themselves.

Clients remarked on how important it was to have somebody who was proactively getting back to them and solving issues, and ‘how fast they made it all happen’.

‘To have someone to speak to who understands 'the systems' and listens and supports.’

‘I got the support I needed. You remembered to call me, I didn't need to follow up. You were very helpful’

‘Very grateful to you for your advice and support - you know your stuff and you're the only person who actually does anything they say they are going to!’

‘At least someone is ringing me and asking how I am rather than leaving me to get on with it like some of the others do.’

### Being listened to – and being available

Being listened to, and having someone to talk to, was one of the most common things people responded to. They often said that they felt like for the first time someone had taken the time to actually listen to them and found out what *they* wanted. Many contrasted this with experiences with health and social care where they felt nobody took the time to listen to them (the PICs also noted that 10 minute appointments and ‘one issue per visit’ was common). As PICs explained it, this meant they have no outlet to tell someone how they are feeling, which in turn adds to their sense of isolation.

“I felt understood. Someone had the patience to listen and hear what I was saying. You thought about how to help me. You are one of the best things that has happened to me and you've given me hope. I'm an expert with my taxicard now - I can go to my appointments and not have to worry about the cost!”

‘Finally someone heard me, someone took the time to listen to me – nobody listened to me apart from the PIC.’

‘Nobody listened to me apart from you’

‘You listened to me and it has been very easy to speak and engage with you.’

‘The PIC always listens to what I have to say and is a good conversationalist as other people I have found do not listen 100%’

‘I felt understood.’

The fact that PICs actively ‘checked in’ and would call back, were ‘always there’ and ‘always had time,’ was also mentioned frequently. Patients felt important, and that they mattered.

### The right people – the importance of the PIC relationship

There were many comments about the kindness, cheerfulness, amiability, authenticity, and genuine care shown by individual PICs. Key factors were that PICs were ‘genuine and authentic’, that they ‘really care’, and were ‘non-judgmental’. PICs noted that by spending time simply building personal rapport, this created a level of trust that meant clients would let them help, where others previously would not.

‘You've helped me so much and we have had laughs together. It has made me feel alive.’

‘You’re a very warm and kind person and you’ve become like family to me. I feel that I can open up to you as you’re genuine.’

‘You’re the one person that’s make me feel worth something and you made me feel like there was help to get. I wish I had know about your service before. I’ve felt that you really care and for the first time in a long time I don’t feel like just a number.’

#### Holistic, comprehensive and wrap-around

Alongside multiple health conditions, most PIC clients had multiple non-health focused barriers that they needed to overcome. The fact that PICs could act as one single point of support and advocacy for a whole range of issues and interventions was explicitly valued by clients.

‘Age UK have been brilliant from start to finish-I couldn't have asked for anything better. After being left searching for answers/help since Nan's strokes, J was a breath of fresh air. She literally held our hand and showed us what was available to us and what help we could get. She was super friendly and Nan loved her visits. J really took the time to understand Nan as a person & her needs rather than just dismissing her as 'another case'. J applied for Dial-a-ride for Nan so she could start getting out and about. She also found us a companionship agency so Nan now receives visits twice weekly. She was a much-needed voice for us when we were having difficulties with carers. I found Jacqui a great sounding board when I needed advice re Nan's care. Brilliant! Fantastic! We need more J's in this world!’

‘You helped me with everything & I couldn't have achieved it on my own and its put my mind at rest (emails from phone, tv licence, council tax, rent, benefits, tenancy were all worrying me!’

‘Done a lot for me. They gave me a chair to sit on for my legs, they gave me a thing to help me when I get on and off the toilet. Also the lady helped me with that form (AA application).’

‘I feel that I've been supported in every way.’

‘I felt really desperate until this lady helped me. A lovely gentleman helped with my shopping and I couldn't be more happier. She helped to arrange my bills and got in touch with my friend from Switzerland for me on this digital thingie when she visited me. Thank you so much.’

#### Always ‘being there’

Many clients remarked on the fact that PICs were available to them in a way that others had not been – that they could call any time, and the PIC always had time for them.<sup>23</sup>

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<sup>23</sup> There was one dissenting view here, who said that they had ‘struggled to get hold of the answering service.’ This was reflected in Healthwatch’s survey, where one respondent complained of the same issue.

### ‘Knowing what is out there’

Clients often reported having no idea that there was so much support available to them – that previously, they didn’t know what was ‘out there’. The knowledge of the PICs, and their ability to help people access that support – and chase up the support proactively - was frequently valued. ‘We didn’t know what we needed’ was another phrase that suggested the proactive and creative approach PICs take, in helping clients understand and better express their needs. There was also a sense that clients appreciated the help in reducing confusion and the sense of overwhelm at the range of services – with somebody with the time to explain, advise, and guide. One client said that there was 'so much support' - if only they had known it existed.

“You have an overview of a lot of things and you are able to tap into the areas to offer an overview to clients of what's available to help them.”

– Service User, Friends and Family Survey

### Healthwatch Croydon survey

As part of this independent evaluation, Healthwatch Croydon were commissioned to provide an additional survey by telephone of 100 clients, who had ended their involvement with the project in the last 6 months. At time of writing, only an initial report has been provided, and is briefly discussed below. The report was conducted by call centre operatives. 64 surveys were completed, considerably fewer than intended, as there was some difficulty in finding clients who were able to participate after an extended period. Many could not remember their involvement, and others were confused about what the service was – they saw it as an integrated part of a wider network of services they have received. At time of writing, Healthwatch’s final report had not been completed, but an initial report of the core findings found that:

- “Once clients had finished the programme, most found that financial issues had improved, and they had support over the physical health issues.
- Clients also had reduced loneliness and increased confidence as well as reduce stress.
- 78% of those asked had felt some significant long-term impact of PICS some months after the programme finished.
- 55% said they could not suggest improvements. Of those who could, most wanted extra support or contact.
- 42% said their confidence had increased; 20% said they had seen no change.’<sup>24</sup>

These results largely concur with the results of the main study, and provide helpful information about the effects of the project for up to another 3-4 months beyond the initial findings. The fact that 81% of clients report substantial improvement is impressive, and broadly concurs with Age UK Croydon figures which show a continued impact after 2 months from last engagement with the service. At the same time, as Healthwatch note, finding out what the difference is for those 19% who did not experience improvement is vital.

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<sup>24</sup> Based on initial Healthwatch figures, updated, November 12<sup>th</sup> 2021.

The survey found that only 41% had increased their confidence, and 21% said they had felt no change. Another 31% were unable to answer the question effectively. As Healthwatch note, there are limitations in the study in that many respondents did not seem to understand the questions, especially around confidence.<sup>25</sup> Healthwatch's recommendations as of November 2021 were that:

- 'For one in six, there was no improvement. While it expected that it would not work for all, an analysis of why they have not seen improvement would be useful to ensure this service works as well as it could for all.'
- 'Could the initial complexity assessment underestimate the time needed to work with them? They may need more encouragement to be independent and further post-PIC interventions are needed to support this.'
- 'Some were confused why they could not go back to Age UK Croydon for PICS. Clearer explanation of the fact that this is a referred service from GPs would manage expectations.'

Suggestions later in this report about termination and post-PIC activity could go some way to addressing the second recommendation, while the first should be part of any good ongoing monitoring and evaluation of the service. Data on the characteristics of the clients and the difference in their outcomes could be a strong place to start, as well as following up with clients who did not feel there had been any improvement.

### The PIC Point of View – Critical success factors

The focus groups run with PICs at the outset of this work showed a team who were extremely dedicated, demonstrated a great deal of confidence and expertise, and had a clear understanding, not only of their own work with clients, but the management and structuring of the service. They gave a particularly clear account of their supervision arrangements and the balance between flexibility and autonomy, and rigorous but supportive team management. They were an impressive team.<sup>26</sup> PICs identified the following critical success factors in achieving successful outcomes.

#### Flexibility within a rigorous supervisory framework

PICs appreciated the flexibility and autonomy that their role had, and indeed, needed. At the same time, they were aware of the need for clear supervision and a rigorously managed framework within which to work. A supportive team who worked hard to ensure they shared information was also in evidence, and they appreciated having a team with ever-growing and shared knowledge of 'what is out there.'

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<sup>25</sup> Further work on understanding to what extent confidence in using health services is built by the project would be helpful – but will likely best be based on analysis and understanding of behaviour change, rather than direct reporting by clients who may understandably be far more aware of the practical differences the service has made to their life than questions they may perceive as more abstract. As we may see from the confusion in interpretation of the question, confidence can be a somewhat nebulous – and generationally distinct – concept. Self-efficacy – which can be measured by more objective and external factors – may be something that could be better measured - and indeed, there are specific questions on the Short Warwick Edinburgh score which could go some way to interrogating this question more effectively.

<sup>26</sup> These focus groups were run part of the evaluation, to look at the effectiveness of the team and its management, as well as to understand more about the work in general.

### Taking the time to build relationships

PICs were clear that with many clients it took a good deal of time to build trust – and this was one of the reasons that the length of intervention was important. This often meant that clients would let them help them with things where others had not been able to *break through* - for example, previously they might have refused to get help with benefits - but because they trust you, they will let you help. They also noted that the fact that they were not seen to be a statutory service meant others would trust them when there was sometimes anxiety about involving 'officials'. Some were especially wary of social services, for example.

### Active communication and follow-up

PICs mirrored clients' feedback on the need to give clients 'live updates,' and maintain active communication with clients – not leaving people waiting, and 'doing what you say you will do.' If nothing else, this helped reinforce the difference between the service and clients' previous experiences.

### Building 'bridging' relationships to independence

Providing support for clients to get 'over the threshold' with other services, eg. 'holding people's hands' to appointments, was seen as vital. PICs spoke of how they promoted independence by helping clients make the first step to connect with a GP, helping them build an initial relationship, so that in future, they felt more able to do it on their own.

'When you go initially and people lack confidence, or forget things, you're able to prompt them, you're able to help them remember things that they need to remember to tell the GP, and you can advocate for them. It means that things aren't missed.'

- AUKC PIC

One example of working to improve a relationship with health professionals was of a man with personal hygiene issues, and behaviours that could be disruptive. Despite best intentions, the GP surgery found it hard to deal with him because he would come to the surgery, sit for hours before the appointment, and put others off coming into the surgery or using the waiting room, partly due to personal hygiene issues, which would then lead to complaints which the surgery had to deal with. The PIC was able to talk to the patient about those personal hygiene and behaviour issues, and help change behaviour, making it more possible for the client to attend, and the surgery to work with them more effectively in future. There was now a much more effective relationship, with GP practice and patient able to accommodate each others' needs for the benefit of the patient.

### Let the client lead – 'It's about *their* goals.'

PICs thought that the goals/ enablers model, starting with its guided conversation, ensured that clients retained a sense of 'dignity and choice' which could otherwise feel was missing in the patient's care. While of course they had to take seriously any safety issues they recognised, and always aimed for the best and safest outcome for the person concerned, they also talked about the need to avoid taking a purely normative model where they 'decide what the right way for a person to live is' (PIC focus group).

A contrasting example was given of a man with hoarding and home hygiene issues who was taken into hospital, who 'had a [statutory service] coming and completely blitz cleaning his flat,' leaving it

unrecognizable when he returned home. This left him very distressed and unable to sleep in his bedroom, which was much worse because he had a memory impairment – he felt he no longer knew ‘where anything was’. A PIC spent a good deal of time with him on his return helping him rebuild his sense of understanding of where things were, and also, helping him replace the furniture he had lost – since all that had been left was a bed. While this may have been in many ways a sensible and possibly necessary intervention, PICs (and the client) also viewed it as an extreme example of the ‘intervention-led’ approach that some professionals warned about in their interviews. PICs thought there needed to be a better balance between dealing with serious safety issues, and doing so in a way which preserves the dignity and choice of the client.

PICs are mindful and careful in navigating this balance – even if they say it can be a struggle at times. At the same time, they were clear that they knew when clients needed ‘a bit of a push’ – sometimes their encouragement sat alongside some constructive challenge, to help people become more independent and make the changes needed to achieve their goals.

“I often say to clients, ‘I’m not Paul Daniels. I’m your Debbie Magee. I can hand you things, and help you along, but you’ve got to be in charge.”

– AUKC PIC

#### Problems with external waiting lists

The PIC service does not have issues with a waiting list in itself. Instead, PICs did note that they often faced issues with long waiting lists for patients in external services. In particular, services around mental illness, dementia, and occupational therapy were often delayed. They were well aware that these are (well-known, and oft-reported) systemic problems for the health and social care system as a whole. Nonetheless, in the case of some of those issues – especially for dementia and mental illness – this could cause significant issues for the PICs, who could find themselves feeling they needed to provide support they were not qualified for. Again, this relates to the need for appropriate referrals around mental illness and dementia, and indeed, for the PICs to be clear about what they can and cannot take on – having the confidence to say no, and recognising their own limitations. On the less serious, but nonetheless important end of the spectrum, over the course of the pandemic, having social activities to refer older people to has also been difficult – and it is an ongoing question as to when and how much previously existing opportunities will return.

#### Termination of relationship

Ending any kind of professional care relationship can be difficult, even when managed very closely. This is of course the case for other types of more formal relationship-based services such as talking therapies. PICs are clear about the length of the relationship throughout the intervention, and careful to remind clients of this throughout. However, it is both unsurprising and to some extent unavoidable that some clients (and PICs) will sometimes feel a strong sense of loss when the relationship ends. The need to find other forms of social connection, and other people to continue to provide a caring relationship with the older person, is strong, but it can sometimes be the case that an older person does not realise that they are lonely, and does not identify increased socialisation as a goal at the outset. Nonetheless, this seems like an area that could benefit from clearer pathways towards alternative and more sustainable social connection.

## Recommendations

### Serious Mental Illness: promoting responsible referrals

The PIC interventions have proven very successful for mood disorders. However, a lack of support for more serious mental illness is an issue across the health and social care system, and PICs have sometimes borne the brunt of this lack of appropriate support resource. PICs themselves and several NHS professionals were able to think of examples of extremely inappropriate referrals of people with SMIs, and inappropriate referrals of people with very serious mental health problems have not only been unhelpful for the clients, but have also had a highly negative impact on the PICs themselves as professionals who are not trained to deal with, for example, people suffering from psychosis or those who are actively suicidal. All agreed it is vital therefore that professionals refer responsibly, and with a full picture of that person's needs.

Overall, however, one of the biggest challenges mentioned, especially by the PICs themselves, was accessing appropriate mental health support from statutory services. Waiting lists meant that PICs were often left supporting people with much higher levels of need, at least temporarily, simply because they had no other avenues. It is hoped that the creation of the Mental Health PIC Service in Croydon will go some way to ameliorating this issue, since the organisations running that service are more expert in dealing with SMI.

This is not a simple problem, and there are no simple solutions. Some potential actions could include:

- Communicating even more clearly about what constitutes a suitable referral with referring partners within the NHS and beyond
- Following up with partners, at a senior level if necessary, where inappropriate referrals are made, to ensure shared learning
- Further training for PICs, at an early stage in their tenure, in how to deal with 'red flags' for serious mental illness (building on their existing mental health first-aider training)
- Continuing involvement in development of a mental illness care pathway – perhaps in partnership with Mind in Croydon, paying attention to the potential crossover between needs/ client groups
- Helping PICs to accept the fact that there will be occasions where their inability to help may mean that the client simply does not receive any kind of help at all – and this is out of their control.

### More structured termination

As mentioned earlier, in a few cases, clients and PICs find that a relationship is hard to end, or to transfer to other, non-time-limited relationships. In many cases, PICs are able to actively reconnect clients with neighbours and family, set up befriending matches, signpost (accompany to) to social activities, or connect to social prescribers. However, PICs noted that for many clients, 'letting go' was very difficult, and they could not always be sure that the client would have the interpersonal support they had offered after the end of the intervention. One respondent said 'I don't want anyone other than my PIC', and several remarked on the shortness of the intervention, or lamented that it 'couldn't go on for ever'; 'Shame it's so short,' etc.

PICs noted that a common issue was that in the goal-setting, older people do not necessarily identify solving social isolation as one of their goals. Many would not identify as lonely or see their isolation as a key issue, even if the issue is obvious to outsiders, or indeed, they may fear attempts to 'solve' their isolation if they have lost their confidence, or even become agoraphobic. Sometimes clients only become aware that they are socially isolated towards the end of the relationship.<sup>27</sup> Some PICs were adamant that the need to be client-led meant that they could not 'force' someone to have reducing social isolation as a goal, even where the PIC clearly perceived it.

While remaining person-centred, and focused on choice and dignity, is paramount, there could be ways further develop approaches to this. Some solutions could include:

- Treating loneliness and social isolation as a given in most cases, and including this as a shared goal across the service – where, at least privately, all PICs make a specific plan for this aspect of their intervention at the outset,
- In doing that, PICs taking a more preventative role, by actively offering, and encouraging, routes into other supportive social relationships as soon as possible,
- Considering practical activities which may aid development of parallel/ concurrent social relationships which can be 'handed over' to independence later, in much the same way as is currently done with GPs and health professionals. For example, being accompanied by a volunteer befriender on several home visits, to create a process of active transferral of the interpersonal relationship to a more sustainable source
- Developing a specific 'Post-PIC' socialisation activity such as a regular tea morning, where previous PIC clients can attend, and perhaps see their PIC again, in the context of a wider group in which more friendships and voluntary relationships could be developed/ fostered.

In all the above cases, clients may simply not want to take part, and again, dignity and choice must be respected. But a clearer pathway for social isolation, and a(n even) more proactive approach, may better help those who have most difficulty building and maintaining social contact – or in identifying their own needs.

Of course, as Healthwatch's report recommends, it may be possible that the PIC service simply needs to work with clients for longer. There is a question as to whether is possible within resources, and the PIC service works with patients, with no limit on the amount of hours spent on support, for a comparatively long time set against other services. Given that part of the goal is to build a wider network of support around the client, and to create greater independence within the context of that support, finding other ways to provide further ongoing sustained support should be a priority. The possibility of referring to the service at the end of the intervention is of course always possible at the discretion of the service, and any referrer.

### Further work on managing caseloads in the face of increasing need

There is always a danger of dedicated staff taking on too much work, especially in more flexible environments, with passionate and dedicated staff, and especially where they may feel pressure from an overstretched system. At a service level, the pressure to prove the value of the service, and

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<sup>27</sup> Similarly, some clients will be very stoical, and say they are 'fine', partly because admitting loneliness may have a stigma attached to it.

offer the low costs that undoubtedly form part of the attraction of non-statutory service providers, can cause difficulties in asserting the boundaries of what is and is not possible.

Again, this is not a problem with an easy solution, but various management strategies could contribute. These include:

- Continuing to communicate clearly and confidently about the limits (as well as the considerable benefits) of the service and what is possible with the resources available, with partners across the network, and commissioners. The PIC Service's existing, highly trusting and constructive relationship with supportive commissioners, as well as a wide range of health professionals, is one of its key enablers here.
- Considering use of the complexity tool to identify where particularly challenging cases which require the support of the most experienced PICs, and
- Using the complexity tool to identify what level of support clients will need at the outset, and using this to manage caseloads/ staff time, as well as length of intervention – with the risk that a transfer to a different PIC in some cases may work against some of the benefits of having a single PIC throughout
- Building staff's ability to say 'no', and to communicate with referring services and partners about what is, and is not, possible. PICs say they are already empowered to do this, but constant reinforcement tends to be necessary with the most enthusiastic staff, particularly in the VCS.

At a last resort perhaps, the service could consider limiting the number of hours available per client. This would be difficult to manage, however, and worst of all, would create a fundamentally different service which would lose many of its unique benefits.

### More pathways, and development of further training

There was enthusiasm for developing further care pathways for some of the most common issues PICS dealt with, especially in light of the expansion of the ICN. PICs' involvement so far in other pathways (including dementia and end-of-life) was felt to have contributed to the development of better planning, of new services (such as plans for a dementia one-stop shop and a 'death café'), and also to the development of high-quality training. PICs themselves also found these pathways extremely helpful, especially when they were new to the role. This training could also be rolled out to the wider ICN, sharing the learning and expertise of the PICs across the wider network.

### Explore more preventative and 'proactive' PIC activity

Many of those interviewed across the board suggested expanding PIC activity further 'upstream', so that clients were actively sought out and issues solved at an earlier stage – before they reach GPs. In many ways, this is exactly what the recent community referrals approach is intended to do. Similarly, current PIC attendance at outreach events such as Talking Points, are all part of this process.

Nonetheless, exploring how the service could do more of this if of value. Further approaches could include advice one-stop shops and pop-ups in 'high-need' spaces, offering a very basic signposting service, or indeed, identifying people with nascent issues that require help early. Another possibility to consider is more active outreach into particularly high-risk/ high-need environments, such as Care Homes

All of this merits exploration, but does also need the caveat that the service is already stretched. Where will the resources for further preventative, or a new, earlier ‘tier’ of service, come from? Care would also need to be taken not to unnecessarily duplicate what other provision there may be in the VCS and across the ICN

### Further connections and communication with the wider VCS

Finally, the service seems well-known and well-respected in the NHS, and was well-understood by the professionals interviewed here, but there would be a benefit more clearly communicating the role of the service across the wider VCS. PICs also noted that they would like to do more to connect with the very small community sector organisations and activities as lockdown ends.

A concerted effort to build further relationships with the VCS, and especially the smaller community/micro-groups could be of great value, not only in terms of identifying further people who need help, but in terms of providing more opportunities for care, community, and support for PIC clients, based in their own community. Doing this is not without a resource requirement – connecting to micro-groups needs a lot of ‘shoe-leather’ and patient building of networks. Nonetheless, the benefits shown by this kind of work already suggest it will be worth the outlay. The ICN+ development offers an even better opportunity to do this effectively.

### Exploring a rich dataset

This study has focused on qualitative data, alongside the headline figures on outcome and outputs. What is clear, however, is that the PIC service has an extremely rich quantitative/ statistical data set which could reveal interesting insights. As with most small VCS organisations, AUKC does not have the resources or the skills that would be needed to make the most out of this data, beyond the (high quality) performance information they provide to commissioners. Therefore, resourcing the support of data specialists – from the CCG, or other sources – to analyse and explore the data set could provide an opportunity to better make the case for this kind of service within the NHS and beyond, given its clear focus on outcomes, rather than outputs alone.

Multiple changes of database and personnel have left some gaps in that data to date, (although it remains usable), and with the above in mind, it is recommended that Age UK Croydon staff have further training in capturing data (and the time to do so), to make the best of this opportunity.

## For further exploration

### Depression and Anxiety

Depression and anxiety were one of the most common reasons for referral (taken together, depression and anxiety were the second most common reason for referral after mobility issues). Medical professionals noted that this was of course one of the most common co-morbidities alongside all the other health issues and long-term conditions experienced by older people. More than one professional noted that older people’s grief at their loss of independence, and ‘all the things they used to be able to do’, is a key problem. There is also an issue with overmedicalisation of a problem which is not necessarily medical. This can mean that, by helping clients get some of that independence back, PICs can have a substantial impact.

All professionals narrated a clear logic chain that showed how the PICs made a substantial difference to this. It was noted that there is a reciprocal relationship between inability to cope with tasks/ poor quality of life, and anxiety/ depression (and ‘disentangling cause from effect is difficult’ - Local GP). Depression and anxiety often have very practical causes (‘situational depression’): often, mood disorders are perfectly reasonable responses to having a miserable life. In those cases, simply making life less miserable may reduce situational depression.<sup>28</sup>

‘For example, older people who are isolated and can’t get people to visit them because the house is horrible. But if you clean the house, that might help the isolation, because people want to visit again. Then you help their anxiety and depression.’

- Commissioner

While there are many social factors which affect people’s mental wellbeing, perhaps the PIC service offers an especially effective approach to dealing with situational depression by dealing with directly with the *situation*, rather than starting with the depression. This may be important learning that could be further investigated in the context of the wider NHS approach to dealing effectively with mood disorders. When the PIC’s listening, supportive, person-centred relationship is added to this – giving patients a sense that they matter – the effectiveness of the overall approach may well be magnified.

### Outcomes and Evaluation - Hospital data

Age UK Croydon worked with the Commissioning team of NHS South West London to gather data on hospital use before and after PIC service intervention. It was hoped that there may be a clear reduction in the number of emergency hospital admissions and A&E visits after interventions. However, none of those involved could identify any clear trends in the data in any direction.

It would be premature to assume that this suggests no impact. First, this was a small sample size (131 patients over the course of 3 months). Second, there was no baseline for comparison – there is no way to know whether the number of people who continued to, or began to, visit hospital after the intervention was more or less than the norm. A control group would be one way to investigate further, although again, experimental design involving a sufficiently controlled environment to provide clear results would be problematic.

Beyond that, there are other questions raised. For example, is secondary care where any benefits would be best demonstrated? One GP noted that when a patient is at the stage where hospital admissions are a likelihood, it may be too late to ‘make as much of a difference as you would like.’ Primary care practitioners were clear about the benefits of the service in their work, so it may be that looking more closely at that field of care will be more telling – and will have an impact ‘further

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<sup>28</sup> In some quarters this has informally been called ‘Sh\*t Life Syndrome’ (SLS) by medical professionals who see very real, tangible reasons that somebody would be depressed – which cannot be dealt with by medical means. See, for example ‘Left behind: can anyone save the towns the economy forgot?’ Sarah O’Connor, the Financial Times, November 16<sup>th</sup>, 2017 <https://www.ft.com/blackpool>

down the line.’ As with any preventative activity, however, that will be even harder to measure in clear financial terms, except at very large, population, scale.<sup>29</sup>

There are also, of course, myriad other environmental factors, and a whole system of other interventions affecting the outcomes. The service itself ‘treats’ many different issues, and deals with hundreds of different enablers, which would make it extremely difficult to find points of direct comparison. Additionally, the PIC service is one part of a much bigger, systemic project overall (the One Croydon model of care), and it may be at that level (with a whole population) that overall trends could be seen. The commissioner notes that this was emphasised in a return on investment review undertaken in 2018, and an economic review of the model of care in 2019, which found an overall 15% reduction in non-elective admissions. With almost infinite variables, identifying which service within that made the difference would always be problematic. These are fundamental questions relating to medical and scientific epistemology as much as they are any comment on particular interventions.

Overall, finding exactly where and how a financial change is made for a service of this size and character will need a sophisticated approach – standard medical/ financial metrics are unlikely to capture the value of a service so different from a standard medical model. The question may require a paradigm shift, or indeed, a need to compromise on evidentiary approaches. However, compromise does not mean ‘to a lower standard,’ but, rather, to a negotiated framework which blends qualitative and experiential data, with the kind of data that medical and healthcare management frameworks tend to use. This is likely to be part of the cultural shift argued for by some of the NHS professionals interviewed here.

## Conclusions

The data collected here demonstrate that the Age UK Croydon PIC service has shown significant and often transformative effects on the wellbeing of its clients. It makes a significant difference to the mental wellbeing of its clients, demonstrated by a nationally recognised scale. These positive effects on mental wellbeing continue in a majority of recorded cases for up to 2 months, and surveyed clients reported a more general positive impact for up to six months in the Healthwatch survey. Data on hospital admissions give no clear indication of whether admissions are decreased by the service, but all professionals interviewed questioned whether that was where any impacts would be demonstrated, and if so, at what sample level.

Client feedback shows repeated references to clients feeling more able to cope, and of taking a more active role in their health and wellbeing. Clients especially value the emotional support offered, and often feel they are being listened to for the first time. They also value the practical support and changes that are made. The holistic, wraparound nature of what is offered, and the fact that goals are set by clients, is stressed as a strength by PICs, and born out by client feedback.

All of the health and social care professionals interviewed valued the service highly, particularly in terms of the practical support it offers, and the ‘route in’ to the voluntary sector that the PIC service provides. They also saw the value it provided in terms of reducing loneliness and providing

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<sup>29</sup> The Commissioner also noted that a return on investment analysis had been undertaken on the ICN model, and had concluded the same.

emotional support they do not have time to give. Many saw it as an invaluable part of their work, and some NHS professionals in particular spoke of it providing a whole new area of non-medical support that allowed them to work more effectively and provide better patient care. The PIC service was also seen by several NHS professionals as an exemplar of a new approach to healthcare which takes more account of the subjective experience of health and wellbeing, which they would like to see more widely adopted in the healthcare system. In the VCS, the service was still seen as of value, but the existence of coordination and one to one support across many other community organisations was raised. Those interviewed did not have clarity on what exactly the PIC service offered, however, and this ought to be addressed.

For the future, work needs to be done with partners to promote responsible and appropriate referrals, especially where clients have serious mental illness. Perhaps relatedly, increasing demand and reduced capacity in other services will mean there needs to be ongoing care in managing caseloads. While expanding work to be more preventative and proactive would be desirable, this too has to be considered in the context of tight resources. The service could look at more developed plans for termination, especially as it relates to the social and emotional support clients need.

Finally, although already seen as a well-networked route into the VCS by clients and the public sector, the service may also benefit from further communication of exactly what it offers, beyond the NHS and social care, into the voluntary sector. Building closer relationships with that sector as a whole has already been agreed as an area for development by Age UK Croydon staff at time of writing.

## Appendix 1: Case Studies

The following case studies have been selected to demonstrate examples of effective partnership working.

### Bernard

Bernard is a 95 year old man living alone in a 3 bedroom house, and was supported only by his step son, granddaughter and their family who live a considerable distance away. He had frequent falls when out shopping, had increasing forgetfulness and confusion, and worsening sensory impairments. He needed to use the toilet often at night, but had a bathroom on the ground floor only – and was unable to use the stairs in home safely. All of these challenges had left him feeling vulnerable, and he said he felt a lost sense of pride.

The AUKC PIC worked closely with his Granddaughter, AUKC Personal Safety and Falls Prevention, a Social Worker, GP and Community Pharmacist, to move from to new extra-supported housing near his family. The PIC provided statements to support the move, and provided regular updates to everyone involved to form a network of support until he moved into his new accommodation. Meanwhile, she applied successfully for Attendance Allowance. Meanwhile, the GP carried out investigations regarding his frequent falls, toileting issues which may relate to his prostate, and hearing and eye tests, resulting in a referral to Moorfields to investigate his cataracts. With the added confidence the PIC provided, the family were better able to engage, and accompanied him to his GP and hospital appointments.

Bernard is now safe in more manageable accommodation, with a smaller flat on one level, and a wet room he is able to use independently. He has extra support from carers on site who provide personal care, and help with his meals and medication. His family are much closer now, and able to visit more regularly, go out shopping together and ensure he gets to all his GP and hospital appointments. Most importantly, they are able to spend quality time together. He now receives higher rate Attendance Allowance payments, and has used these to purchase a four wheeled rollator, and is saving up saving up for a riser recliner chair. Age UK carried out a safety assessment and fitted additional handrails in his new home. His new neighbours have been very welcoming and have invited him for tea and cake.

As a result of the PIC service's joint working with a range of services, Bernard is safe in his accommodation, better off financially, and is having his medical needs looked after with support from the right NHS services and people to advocate on his behalf. Vitally, he is reconnected with a family who cares, has a burgeoning local social network, and feels a greater sense of pride and wellbeing. With the right support, he is able to live much more independently.

### Kenneth

Kenneth is a 92 year old man, who lives alone since his wife died in April 2020. He has multiple health conditions, including macular degeneration, cancer, heart and kidney disease. His accommodation was unsafe in many ways - his home and garden had become infested with mice and rats, and his whole living area needed clearance and deep-cleaning. He was struggling financially, and his visual impairment meant he was unable to contact the different services he needed, or to undertake essential paperwork.

The AUK PIC agreed a series of goals and set about applying for Attendance Allowance to ensure he received the highest rate. With the additional income, he was able to hire private pest control services to remove the mice and rats, and to get waste collectors to clear his living spaces. The PIC also helped him arrange a cleaning company to do a 'blitz clean' and arrange for a regular cleaning service since he couldn't manage on his own. A local gardener agreed to maintain his garden as a volunteer whenever he is in the area. Bills were set up on direct debit to avoid him needing to complete complex forms or inline payments, while neighbours agreed to read letters for him and help him pay the bills. He also received a referral to a podiatrist to ensure his mobility and foot health were maintained.

Kenneth is now much safer, and lives in a clean, hygienic, tidy environment that he is able to maintain going forward. With more money, simplified administration, and friends and neighbours to help him in future, he has a sustainable way to manage his own finances and pay bills on time, while the support of a kind local gardener means he can continue to enjoy his garden in the future.

Kenneth can live safely, and sustainably, with the highest possible level of independence, with just the right amount of support – much of it provided by other members of his community. He says 'I feel a bit safer and much less vulnerable since the PIC service was introduced'.

## May

May is an 89 year old woman who lives alone. When the community pharmacist visited her, she found she was quite lonely, had become fearful of going out, and was struggling with low mood. As well as suffering from COPD, her vision had deteriorated rapidly over the last year, and she needed help obtaining hearing aid. A recent fall had left her nervous in the bathroom, and having to strip wash. While May cooked for herself, and her sister helped with shopping and cleaning, she was struggling with these tasks, and didn't want carers. May didn't know her neighbours, and her only regular contact with younger sister and older brother, by phone. Perhaps because of this, she tended to ring her sister at all times of the day, which was causing problems. Her sister and brother-in-law, were also Carers for M's older brother, and they found it hard to cope. Her sister believed she would be better off in Residential Care, and was concerned about her falls, and ability to cope in general. Other people around May suspected she had dementia.

The AUKC PIC met May and agreed some goals to improve her situation. She first arranged and accompanied May to an optician's appointment, who then made a referral to the Low Vision Clinic for macular degeneration. She also arranged a podiatrist appointment, and chased up a longstanding referral to a Hearing Clinic. They attended the GP to discuss her low mood, and liaised with the Community Pharmacist about her medication. To make sure she was safer in her home, the Pic referred her to the AUKC Personal Safety Project, arranged for a Careline, and applied for Attendance Allowance to help cover the cost. This also paid for a regular cleaner and carers 3 times per week. . In order to help her get out more easily, the PIC helped her apply for Taxicard and Blue Badge.

May is now safer in her home with Careline, a Key Safe, adaptations & equipment, and carers and cleaners. Her eating has improved, and she is bathing regularly, while she is taking a more active role in managing her health conditions after input from the Pharmacist, Hearing Clinic and Low Vision Clinics. Her financial pressures have been reduced with the receipt of Attendance

Allowance Higher Rate, Blue Badge, and a Taxicard. Meanwhile, she enjoys the company of the Carers and Cleaner who visit – she also finds that she now have more “social” rather than functional visits by her sister, who has time to talk, not to clean. Her sister reports that she is much happier at home, and she doesn’t receive calls in the middle of the night anymore.

The PIC mobilized the support of a whole range of professionals, using the range of support that was available, to allow May to manage her day to day living independently and safely in her own home. Her sister and brother in law are more able to care for her and her older brother, but feel reassured now that she is able to manage in her home safely. This has greatly improved her relationship with her family, and there is no more talk of May going into a care home.

## Appendix 2: Healthwatch Survey Initial Findings

# Client experience of Croydon's Personal Independence Coordinator Programme

Final pre-published draft

November 2021



## Background

Since 2018, the One Croydon Alliance has commissioned Age UK Croydon to deliver the Personal Independence Coordinator (PICs) programme. The clients were previously regular attendees at GPs or hospital services. The aim of this service to help clients become more independent.

PICs work for people between 8 and 16 weeks depending on the complexity of the person and their situation. Initially the contractual agreement was an intervention of 12 weeks for each client. A complexity tool was developed in 2019 and the flexible working timeline was introduced in agreement with CCG to respond to an issue when some clients clearly needed more than a standard 12-week intervention for them to really benefit from the service. Equally some clients only required 8 weeks or 12 weeks depending on their situation, their goals, and their health conditions.

The service is now being reviewed through an evaluation programme to see what impact it has had on clients and suggest improvements to further enhance the programme.

## Objective of project and methodology

- To gain the views of clients on the impact of having a PIC and what could be improved as it moved forward.
- Working with Age UK Croydon, Healthwatch Croydon identified clients who were telephoned interviewed between August and September 2021.
- To avoid any issues of GDPR, all clients were asked to give the consent to comment and then their details were shared with Healthwatch Croydon to undertake the telephone interviews via their Healthwatch Hub team.
- The aim was to undertake 100 of these representing the six localities and approximately 2 for each GP surgery.

- To avoid any recall bias, clients were only contacted within six months of completing the programme.
- This is an initial report to give initial headlines. A further version will be produced with more client views and some additional analysis.

## Limitations

- **Original sample:** There were only so many clients who we could ask who give their views, based on time since they had used the service. We wanted to avoid recall-bias and so limited recruitment to those who had finished using the service in the last six months. This is a small number as a representation of all those who had used the PICS service since it began in 2018.
- **Completed sample:** 64 interviews were completed. This is significantly below the number planned for, but there were challenges in recruiting clients to contribute within the limits of time-constraint for the project and those who had used the service in the last six months.
- **Selection bias:** To avoid any GDPR issues all clients needed to gain their consent. The most effective way to do this was by their PIC contacting them. This meant that those likely to be recruited may well have had a positive experience with their PIC. Some of those with a more challenging experience may not have consented to this.
- **Difficulties with some of the questions:** The question concerning whether clients had increased confidence in using health and care services was not effectively answered by 31%.

## Overall insight and recommendations

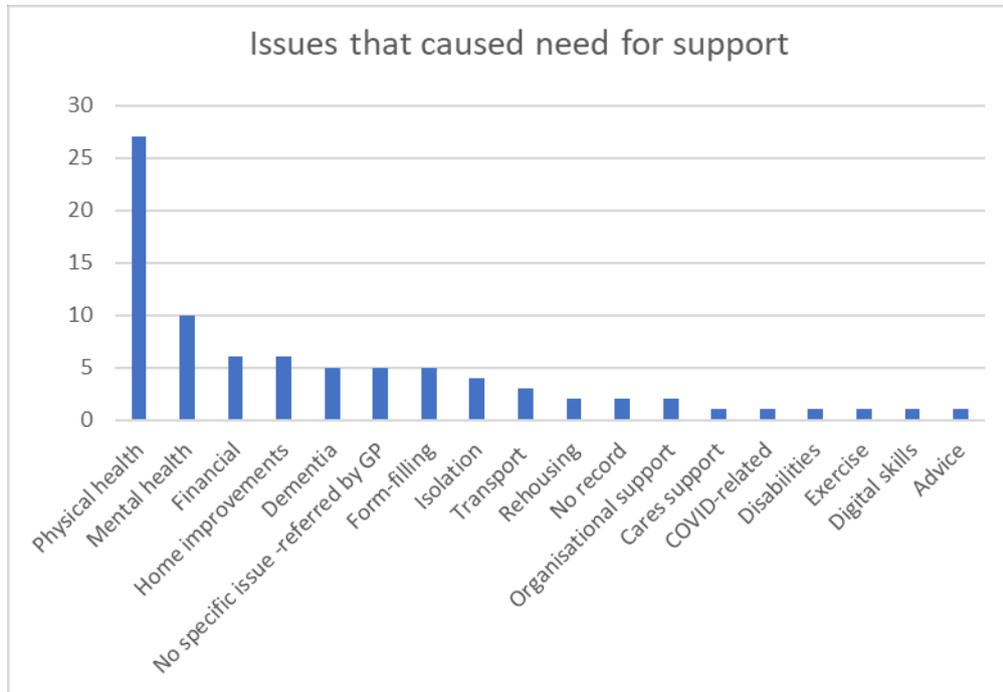
- Physical and mental health issues and managing finance were key issues for clients. Signposting, support, and advice were two of the top areas where people needed help. Issues such as improving homes with facilities to make it easier for clients wanted to live were important, as well as financial issues.
- Once clients had finished the programme, most found that financial issues had improved, and they had support over the physical health issues. Clients also had reduced loneliness and increased confidence as well as reduce stress. However, nearly one in six (15.3%) said they had no improvement.
- 78% of those asked had felt some significant long-term impact of PICS some months after the programme finished.
- 55% said they could not suggest improvements. Of those who could those most wanted extra support (19%) or contact (12%).
- 42% said their confidence had increased; 20% said they had seen no change.

## Recommendations

- For one in six, there was no improvement While it expected that it would not work for all, an analysis of why they have not seen improvement would be useful to ensure this service works as well as it could for all.
- Some clients feel they needs more time with their PIC. Could the initial assessment of complexity underestimate the time needed to help them? It may also be that they need more encouragement to be more independent and further post PIC interventions are needed to support this.
- Some were confused why they could not go back to Age UK Croydon for PICS. Clearer explanation of the fact that this is a referred service from GPs would manage expectations.

# Insights

## 1) What issues did clients have?



N=83

- Physical health at 33% was by far the largest issue, followed by mental health (13%) and then issues to do with financial issues.
- There was a wide-range of other issues but with smaller numbers.

## Views

“I was having a lot of medical problems and <<PIC>> has been giving me help and advice.”

“I live on my own and I got very low during the pandemic. I don't have any family.”

“Wife full time carer and <<PIC>> helped with filling in forms and finding people to do work for, and equipment as husband not mobile. Health and safety advice and extra equipment.”

“My house was cluttered.”

“My dentist took out all teeth and she helped get the hospital appts needed. A whole year without teeth and very helpful to have her support. Had stroke previously and nervous about treatment as gums now out of shape.”

“Dentists messages to hospital not recognised/responded to.? PIC chased and will attend along with me.”

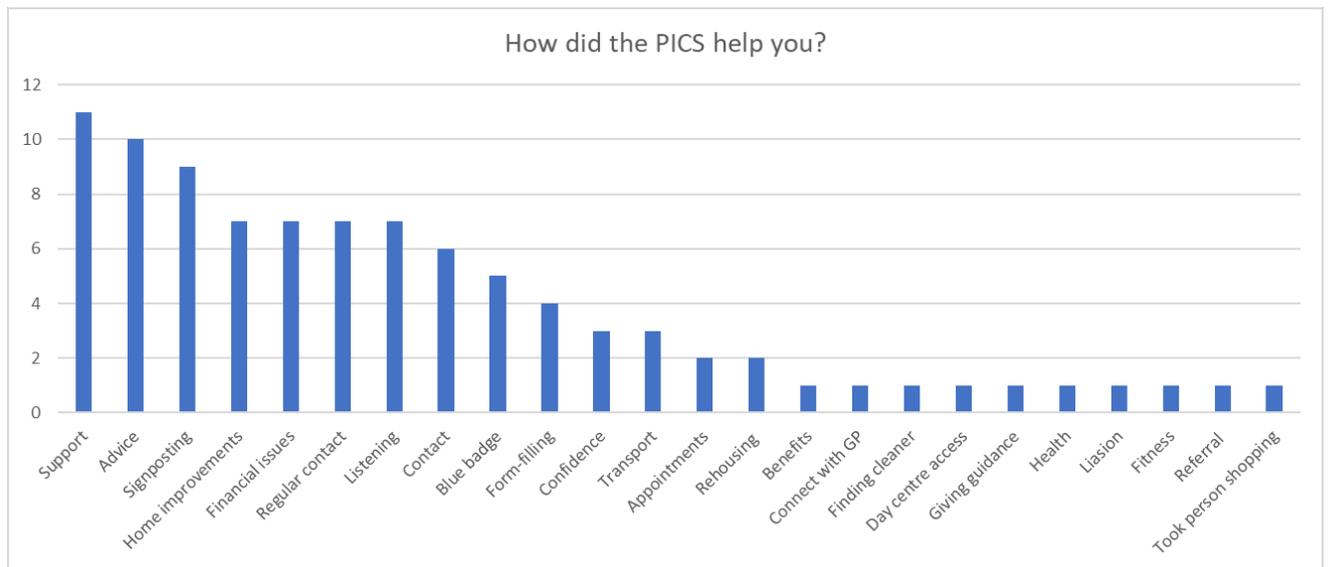
“My wife has dementia. We've used <<PIC>> twice and the last time was to try and find my wife a day centre as the last one closed down during the pandemic.”

“I was having so much family issues. I felt lonely, sad and depressed. The referral came through my GP.”

“I don't know how I got <PIC> but I think through the GP. I'm 81 and live by myself. I live in a large house with lots of stairs - I think that's why my GP referred me.”

“I needed some of my papers sorted out. I can't read and write very well - she read for me and did this and that to-do with paperwork.”

## 2) How did the PICS help clients?



N=93

- Support was first followed by advice and signposting as the top areas where people needed help.
- Issues such as improving homes with facilities to make it easier for clients wanted to live were important, as well as financial issues.
- Listening and contact was also very important for some.
- PICS also helped with a range of administrative support such as form-filling and benefits issues. blue badges and other transport like dial-a-cab and supporting appointments.
- Some enjoyed being taken shopping showing the breadth of help.

## Views

“Guidance helped a lot helped changed my life.”

“Helped me to stop worrying. Very kind and caring and tried her best to deal with my issues. She kept in touch. She was excellent but some things were out of her field of expertise like financial matters so she had to pass me to other people but she did the best she could. She facilitated on advice and pointing me in the direction of people who could help further.”

“In a number of ways. When she visited, she was able to see my situation where I was trying to support another person. Her knowledge and contacts and the support of another member of Age UK helped me get in touch with the Staying Put service and they were able to give me names of reliable and trustworthy tradespeople that they had worked with previously and the Age UK staff member was able to support me in my home in dealing with the tradespeople after a difficult experience for which I was very grateful.”

“She got me help with a rent rebate and council tax.”

“She was a tremendous support. Any problems and I know I can call and she'll help me and give me advice. She'll just be there for me. Several times she has contacted the Dr for me when I was unable to do this. She has looked after my medical needs.”

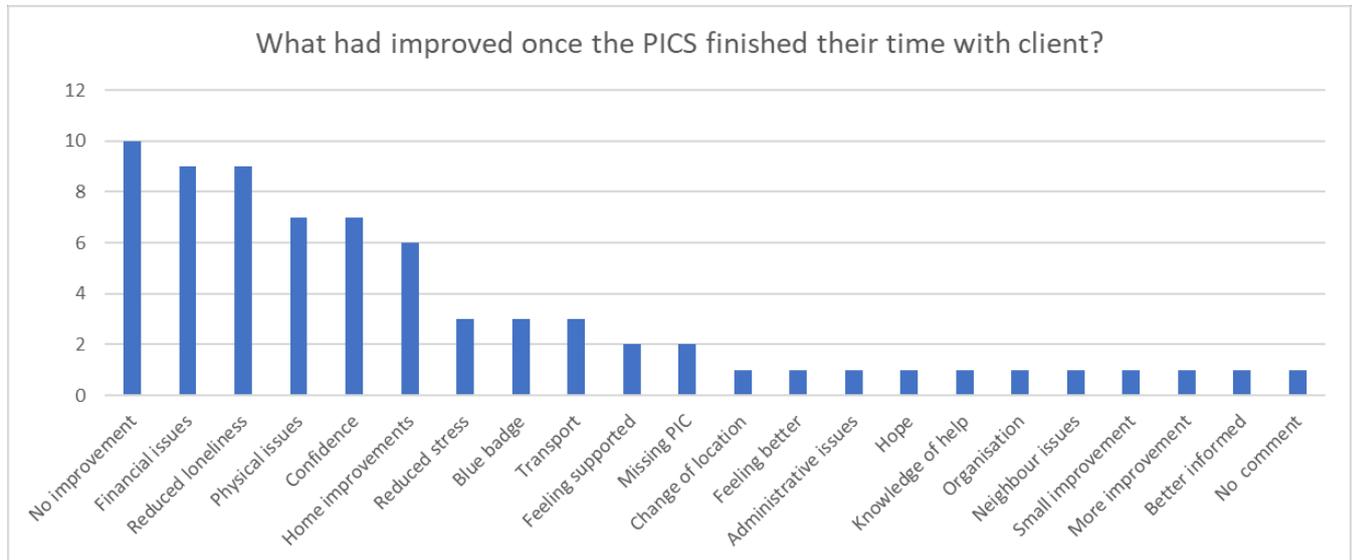
“Tremendous help! Applied for blue badge for son to help him.”

“She managed to get my house cleared. She really put my mind at ease. It was embarrassing but I didn't feel it with her. She's very supportive and is the bees' knees!”

“I needed help with forms and stuff like that. I'm a disabled person, a wheelchair user with cerebral palsy and dyslexia. I don't have any family, so it is very difficult.”

“She took me shopping for shoes. Helped take me to the bank. Helped me in every way I wanted.”

### 3) What had improved for clients once PICS finished their time with them?



N=72

- Most found that financial issues had improved, and physical health issues had been supported.
- Clients also had reduced loneliness and increased confidence as well as reduce stress.
- Not health issues such as home improvements, gaining blue badges and arranging transport also made a difference.
- Ten of the 65 felt they had no improvement.
- Four were missing their PIC at the end of the course.
- Four stated they had no improvement.

## Views

“I am able to organise more. I'm able to declare about what I am not doing.”

“A lot of things - got a bit of confidence that someone was here to help.”

“We now have people who come and do the shopping and prepare food.”

“She helped to explain things and now I feel more confident.”

“Nothing has improved health wise but he has been helpful with supporting me in my benefits.”

“I can't honestly answer that - some things have not changed.”

“All was going very well after <<PIC>> finished her time with me but then I had another death in the family which set me back.”

“Only the financial side of things.”

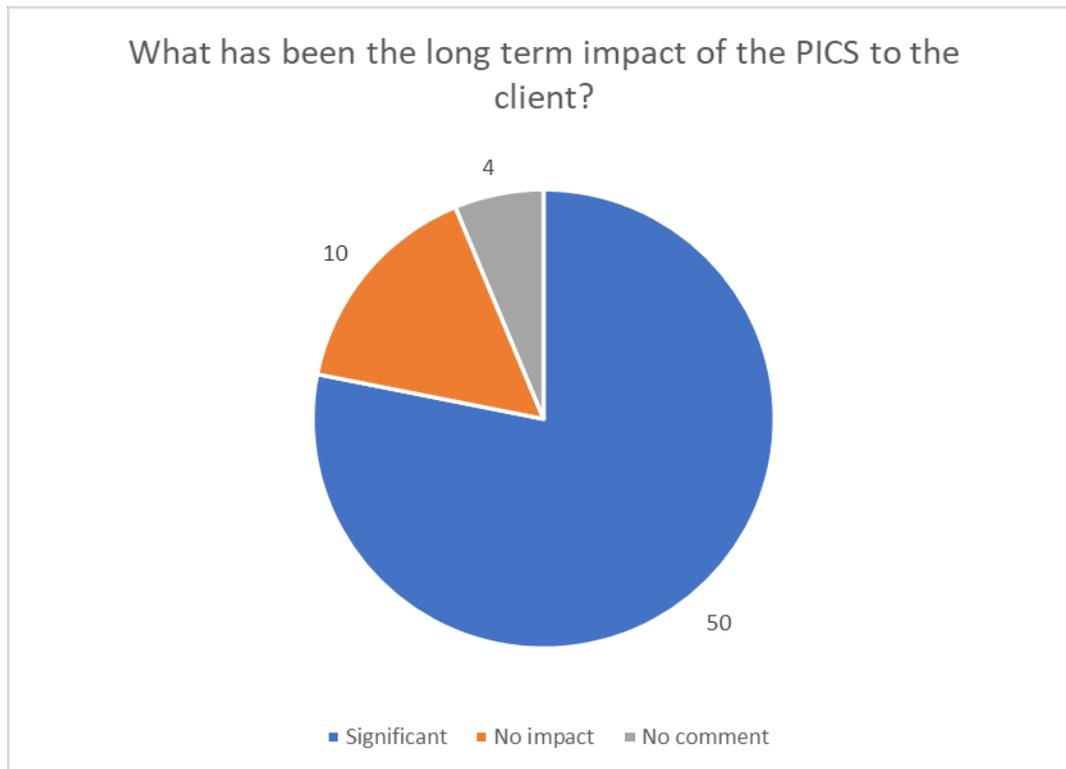
“I have started volunteering chatting with people. We set up Zoom together and I joined a chair exercise classes. I never knew that it would feel so good - I felt so lonely before. I got to see people and interact with them.”

“I was very sad that the time with <<PIC>> stopped.”

“I don't know if a lot has improved, and I have missed her coming.”

“The problems are still there, and I would like help with counselling. I feel a bit better but would like ongoing support.”

#### 4) What has been the long-term impact of PICS to the client?



N=64

- 78% of those asked had significant long-term impact of PICS some months after the programme finished.
- Only 16% said there had been no impact.

## Views

“Talking with her was very beneficial.”

“<PIC> put me in touch with social services so I now have a shower chair. I don't feel as lonely as I did before. I'm also hoping to move to a semi assisted scheme and she helped me think about this.”

“Contact we hope continues but all benefit from these forms and outcomes.”

“I enjoy being at home now all the clutter has been removed.”

“Will be helped at appt and be able to feel much better.”

“There is nothing long term that has helped but <<PIC>> does have a cheery persona.”

“Not really know how to answer but felt better.”

“Made things easier, less to worry about because of her help.”

“Not much impact due to the ongoing needs I have. I would like ongoing support.”

“He has me now to help care for him. <<PIC>> helped to give us both information. I know that I can talk to him.”

“I still need help.”

“Not a lot and I am more lonely then before.”

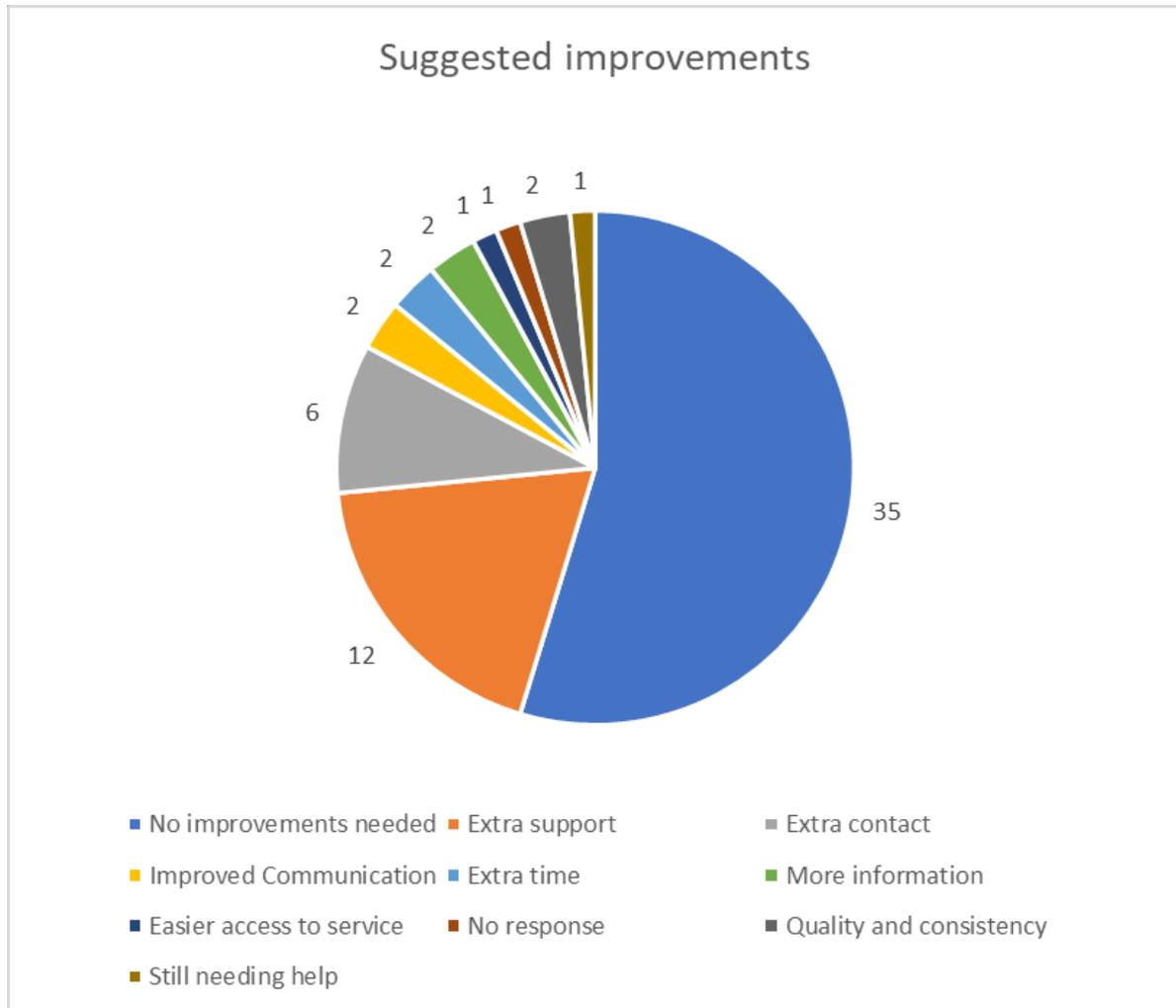
“I've learnt to put things away and have some order.”

“She referred me to a lady for counselling. Going to look into that now and maybe group counselling.”

“I have never had any experience before of AGE UK and I am happy to have my card.”

“She actually phones me to check that I'm ok. Sometimes she thinks I have fallen behind and helps me. I feel supported.”

## 5) What improvements could be made to the service?



N=64

- 55% said they could not suggest improvements.
- Of those who could those most wanted extra support (19%) and contact (9%) time (12%).
- Some wanted extra time at the end of the programme or more information.

## Views

“I would have liked a longer time with <PICS> so she could have helped more.”

“I asked about kitchen repairs as I have a big hole in my kitchen and someone from social services was supposed to come to help but they haven't. I have been on the phone all morning trying to get through to them. I still need help.”

“To be perfectly honest, I don't think there is anything else they could have done. Just being available was so important.”

“I will never run <PIC>> down, she was a lovely woman.”

“I don't know if there could be any improvements. I'm not going start walking much better or running but at least I'm managing now.”

“She still needs help with filling out a pension form.”

“I can't think of anything.”

“Would have liked to talk to her for longer and I miss her.”

“I hope that they all do the job like <<PIC>>. She does the best she can. I don't think it can be improved - if everyone is like her. Brilliant service.”

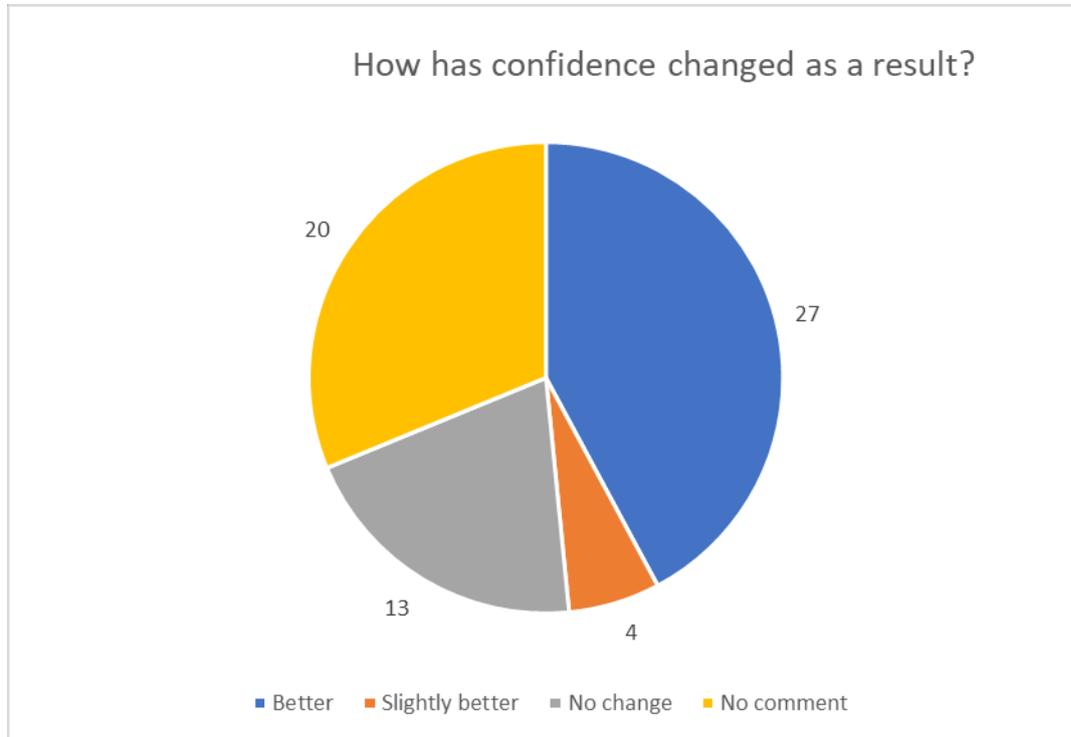
“120/100 for <<PIC>>. Please make sure she knows it.”

“Yes please. <<PIC>> left after a while and I had someone else help me. I would have liked it to progress.”

“Well I would like to see that people who have computer or reading/ Disability issues have additional and ongoing help. Nobody has helped me with it (PC) and I have phoned various people and they cannot help. I have other things that need looking at like health appointments, grass needs cutting, I live by myself so I can get lonely - would like someone to come in and help with those things.

“No and we both like the service. “Would have liked Emmanuel to spend more time with me. I don't have anyone to talk to. I can't breathe very well because of the smell.” (Interviewer wasn't quite sure what she was referring to, but something is setting off her asthma in her flat or near her flat).”

## 6) How has client confidence changed as a result?



N=64

- 42% said their confidence had increased and 6% had seen their confidence increase slightly.
- 20% said they had seen no change.
- 31% had no comment on confidence.

## Views

“Yes, she was always boosting my confidence and encouraging me.”

“I think it was a wonderful service and I would recommend it to friend. My confidence has improved.”

“My confidence is ok.”

“No difference. feeling more confident in all areas.”

“I feel the same. I don't say anything if I don't feel confident in saying it.”

“Not much in other services.”

“Age UK have been wonderful and not so confident with other services.”

“I am more confident but it's a nightmare trying to access community services, it's hard to contact a human being.”

“Most definitely my confidence has improved. Despite everything going on out their people are there that care. It's reassuring”.

“Because of Alzheimer's that's 'tricky to answer' but family felt confident in reaching out to other services.”

“I'm very confident now and I can now speak up!”

“No I haven't reached out and don't feel confident. I still feel very cut off.”

“He is a bit more confident.”

“Yes I feel confident and if it were possible to reach out I would.”

“I need to see the dentist and have tried to reach out to them.”

“I have not reached out to other services but I feel more confident.”

## Quality assurance

### Does the research ask questions that?

**Are pertinent?** Yes, these asked services users how the experience of using the service and the impact of using it in improving their situation as a result.

**Increase knowledge about health and social care service delivery?** This research helps AGE UK as delivers of the service and One Croydon Alliance commissioners understand the impact of an innovative new service. This could also be used to help create new services both with Croydon and beyond/

### Is the research design appropriate for the question being asked?

**a) Proportionate:** The specifications aimed for 100 responses, including 16 across each locality and 2 in each surgery, so reflect the project across Croydon.

**b) Appropriate sample size: Has any potential bias been addressed?** As above, 100 was considered a suitable number of recent service users.

**Have ethical considerations been assessed and addressed appropriately?** Yes, we are interviewing very fragile and vulnerable adults, some who may have dementia. It was designed that they would be asked if they would like to contribute to the study by their PICs and if they agreed their details would be shared with Healthwatch. We also decided that the Hub would undertake telephone interviews as they are specifically trained to take calls like this. If respondents chose to refuse, this was accepted but also recorded.

### Has risk been assessed where relevant and does it include?

**a) Risk to well-being:** None.

**b) Reputational risk:** That the data published is incorrect and not of a high-quality standard. We publish the full transcript and show where we have made inferences, based on what was said.

**c) Legal risk:** Have appropriate resources been accessed and used to conduct the research? There was no need to refer to legal resources for this research.

**Where relevant have all contractual and funding arrangements been adhered to?**

This has been funded by a grant from AGE UK Croydon after an invitation to work on this project. All contractual and funding arrangements have been adhered to. Healthwatch Croydon received £2,000 to complete this work.

## **Data Collection and Retention**

**Is the collection, analysis and management of data clearly articulated within the research design?** Yes, the data would be collected within Smart Survey and then analysed and coded manually.

**Has good practice guidance been followed?** Yes.

**Has data retention and security been addressed appropriately?** Yes.

**Have the GDPR and FOIA been considered, and requirements met?** Yes.

**Have all relevant legal requirements been adhered to ensure that the well-being of participants has been accounted for? ie the Mental Capacity Act.** None required for this research, beyond what is stated above.

**Has appropriate care and consideration been given to the dignity, rights, and safety of participants?** Yes. Participants were recruited and supported throughout the process. Details were only shared after agreement with client. Healthwatch respected the right to refuse an interview.

**Were participants clearly informed of how their information would be used and assurances made regarding confidentiality/anonymity?** These were made clear throughout the process.

## **Collaborative Working**

**Where work is being undertaken in collaboration with other organisations have protocols and policies been clearly understood and agreed, including the development of a clear contractual agreement prior to commencement?** There was an agreement with Age UK on what was expected and when.

Have any potential issues or risks that could arise been mitigated? These are shown below:

Risk factors	Level of risk	Contingency
Cannot get enough participants	Medium	Look to recruit more through AGE UK
Question set does not work with group	Low	Questions and themes were agreed and could be revised if they did not work
Data is seen as being out of date	Low	Report to be completed within two months of insight undertaken.

There was a limitation in this process in that only 64 of the 100 were received. The timescale for delivery as well as availability of relevant respondents meant this was shorter than planned.

In terms of objectiveness, the fact that every respondent was being recruited by the same PIC whose service was being evaluated meant that there could be a conflict of interest, particularly if the rapport between service user and PIC was not positive or service user had a very negative experience which means they may not want to engage at all.

However, in terms of trust and working ethically, recruiting through the PICS seemed the most logical and effective way of recruiting respondents and so this process was agreed, taking into consideration the points above as limitations.

**Has Healthwatch independence been maintained?** Yes, this research is shared with Age UK Croydon before publication for their comment, but only factual inaccuracy would be reviewed. This does not affect the comments of experiences we receive.

### Quality Controls

**Has a quality assurance process been incorporated into the design?** Yes, we assured the process at the beginning.

**Has quality assurance occurred prior to publication?** Data collection was checked and re-checked.

**Has peer review been undertaken?** No peer review was undertaken. It was not required for this research project.

## **Conflicts of Interest**

**Have any conflicts of interest been accounted for?** This project was an agreement between Healthwatch Croydon and the AGE UK Croydon on behalf of the One Croydon Alliance

**Does the research consider intellectual property rights, authorship, and acknowledgements as per organisational requirements?** The research is owned by Healthwatch Croydon, who are managed by Help and Care. It is intended that this will be joint published with the One Croydon Alliance after consideration by relevant boards and committees.