NHS
East Lancashire
Clinical Commissioning Group

Final Report for the Integrated Personal Commissioning Pilot in East Lancashire

January 2019

the calico group

ALOCURA

MyLife

Acknowledgements

The Calico Group would like to thank the following organisations for their input into the pilot over the past two years; in particular, we would like to thank all of the members of both the project team and the steering group, who gave up much valuable time to help in the governance and development of the pilot model.

Pilot delivery and funding partners:

- The Calico Group
- East Lancashire CCG
- Alocura
- My Life
- NHS England
- Lancashire County Council

A more detailed overview of the organisations involved in this pilot can be found in Appendix 3.

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Contents

Executive summary

Introduction

This report is a summary of key findings, potential efficiency savings and recommendations from a 12-month pilot project (July 2017-July 2018) in East Lancashire to test a more effective approach to the delivery of personal health budgets, and personalised care and support.

The project was led by The Calico Group and also included East Lancashire Clinical Commissioning Group (CCG), Alocura and My Life as delivery partners.

This report has been prepared for the pilot delivery partners, but it may be of interest to a wider audience.

The model tested in East Lancashire, and the outcomes achieved, are replicable and show potential to be delivered at scale. Commissioning support units, clinical commissioning groups, local authorities and NHS England staff will benefit from the lessons outlined in the report, and its recommendations to assist with the implementation of personalised care at a local level and to support its nationwide spread.

Background and context

The health and social care systems are facing unprecedented demands due to financial pressures and a demographic time-bomb.

People with long-term conditions and complex needs make up about 30% of the population, and 70% of the NHS budget is spent supporting them.

A growing evidence base shows that enabling people to have greater choice and control over their care and support can deliver better health and wellbeing outcomes, and allow budgets to stretch further.

There is an increasing shift in the NHS towards more personalised care, and one key component of personalised care is the use of personal health budgets.

At the end of 2017/18, more than 28,000 personal health budgets were in place nationally. By April 2019, NHS England expects that, unless there are exceptional circumstances, everyone living in their own home who is in receipt of NHS Continuing Healthcare Funding (CHC) will have a personal health budget.

Furthermore, the national mandate from NHS England for roll-out of personal health budgets is that between 0.1% and 0.2% of the health population will have one by 2020. This is the equivalent of between 450 and 890 personal health budgets in East Lancashire alone.

Prior to the start of this pilot being considered, there were less than 100 people with a personal health budget in East Lancashire, and this number has not increased significantly in the past few years.

To meet the required numbers of personal health budgets mandated by NHS England, a new approach and delivery model is therefore required.

Pilot overview

The overall ambitions of the pilot were to identify 50 people that would benefit from a personal health budget and provide them with a personalised care plan; to secure a personal health budget for 30 out of the 50 people; and to explore the possibility of integrated budgets.

Our focus was on people receiving continuing healthcare or with one of more long-term conditions from the top 30-35% of the population recognised as having moderate to high levels of complex needs and requiring "targeted" and "specialist" care.

By supporting individuals through an end-to-end process of gaining a personal health budget, the pilot team was able to explore current available care and support provision and carry out a detailed examination of the processes involved, identifying opportunities for streamlining. The team was also able to look at financial efficiencies and the potential for a scalable and self-financing model. The pilot also aimed to address wider wellbeing issues and health inequalities in East Lancashire.

The report demonstrates the success of the pilot and provides a strong case for the work of the pilot to be continued. Success is demonstrated in the volume of individuals that we have been able to support; the financial and social outcomes that we continue to achieve; and the engagement and satisfaction of NHS staff involved with the pilot, built around the difference we make to the people under their care.

The success of the pilot means that, since its conclusion in July 2018, the programme has continued to be funded by The Calico Group and its partners in advance of agreement around future funding models. We anticipate the required funding being mobilised early in 2019, which will enable the scaling up of our pilot.

Key pilot outcomes

As of December 2018, 81 people were referred into our programme and, by the end of the calendar year, we anticipate that 62 people will have been progressed to the pilot and will be in the process of having a personal health budget approved; of these, 17 will be integrated health and social care budgets. As noted, the focus has been on people with either more complex or long-term health issues. The average budget value has been £72k for live cases. A review of our forward pipeline suggests that this will increase to an average budget of £134k. This is due to the relationships developed with the referral pathway partners and increasing confidence in this programme.

The longer-term outcomes of the pilot will be fully reviewed on the 12-month anniversary of the project in July 2019. Our methodology in evaluating has been to collect data every three months for each

individual from their induction to the programme. We have utilised the Personal Outcomes Evaluation Tool (POET) developed by Lancaster University and In Control.

Initial data from the POET survey showed people reporting a significant difference to their long-term and complex health and social care requirements, including:

- 48% improvement in re-engaging with their communities
- 40% improvement in emotional wellbeing
- 39% improvement in quality of life
- 36% improvement in being able to exercise choice and control over everyday things.

People also talked about their determination to live independently, improvements in their self-esteem, and in their perceived physical health. A number of families have also been brought back together as a result of a personalised approach to meeting their health and wellbeing needs.

As well as the positive impact on people's lives, this pilot has also identified potential for savings to the NHS. At this stage of reporting, using the Global Values Exchange, we have attributed an estimated value to each person's interaction with health services.

For the 22 individuals surveyed, and working from their recollection of service usage in the previous 12 months, we forecast an estimated 67% reduction in their use of planned health services, and a 76% reduction in use of crisis or emergency services - representing an 84% real cost saving to the NHS based on the programme estimates.

Furthermore, we estimate that this pilot will have created a much wider social impact. At this stage of reporting, we are not able to provide a fully accurate projection of cost savings and value of the wellbeing outcomes. This is because most of the care plans we have produced are in the early stages of implementation and, as such, the required data is not yet available.

However, based on the plans created, and for illustrative purposes only, we have provided an educated approximation of the overall wellbeing impact of the programme. This figure will be further developed and scrutinised over the reporting period to September 2019, with a full social profit statement produced as part of the final report at that stage.

- At present, at a headline position, we forecast that the social value of the wellbeing improvements to the individuals will be £430,000 for the 22 participants.
- Based on information provided by the 22 participants, we anticipate an overall cost saving to the NHS of £1,232,000. This reflects a cost saving of 84% by the end of year 1.
- Our initial workings around this are provided at appendix 2.

Key findings and recommendations

Targeted delivery

The biggest difference can be made with the top 30-35% of NHS users (those identified as requiring "specialist" or "targeted" support). We recommend that commissioners consider the requirements of different segments of the whole health population and tailor approaches to personal health budgets accordingly.

The personalised care (labour) market

This pilot has identified a significant gap in the Personal Assistant (PA) workforce. Through the pilot, we have identified that up to 80% of the requirements in a personalised care market are likely to be PAs. We estimate that, in East Lancashire, circa 4,000 PAs would be required to meet the needs of 890 personal health budgets, assuming that the individual to PA ratio mirrors the pilot in rollout. Commissioners will need to carefully consider how PAs will be recruited and trained in order to meet the demand when personal health budgets are rolled out.

We also uncovered issues with commissioners' expectations of the pricing of services. Social care frameworks have been used as a baseline, but the pricing (for PAs in particular) used for social care does not reflect the skill and capability required of PAs to meet the needs of someone with a personal health budget.

Addressing short-term crisis and wellbeing needs

Approximately 18% of the individuals referred were not eligible for a long-term personal health budget and, as such, would exit the pilot programme. The pilot identified opportunities for the allocation of short-term personal health budgets that would prevent individual challenges, usually found in the wider determinants of health, escalating to becoming complex health issues.

These individuals have come to our attention because they require support, and our partnership recognised the importance of this interaction and put in place signposting arrangements to other services. We recommend further exploration of the use of short-term/one-off budgets for a period of up to six months per individual to help meet these immediate health and wellbeing needs.

We also strongly recommend that that housing, advocacy and market management are viewed as integral parts of the process; without these wider areas of support, personalised care cannot fully be delivered in relation to short-term needs, and more generally in personalised care.

Integration and funding

Whilst this pilot has been successful in delivering integrated personalised care and support plans incorporating both health and social care, it has proven difficult to make integration happen beyond the planning stage. Much more work is required in this area.

Funding for the implementation of personal health budgets locally is a potential barrier, particularly as personal health budgets are rolled out at pace and scale. We recommend a full review of existing funding to identify how this can be restructured and redirected into the delivery of personalised care. This includes looking at the disaggregation of block contracts.

The pilot also uncovered lengthy delays in the approval of integrated budgets incorporating both health and social care funding. We recommend establishing multi-agency panels, with required delegated authority over budgets to enable smooth and timely approval.

Culture change

We have been surprised at the level of resilience and persistence required to move this pilot forward. Delivery partners in the pilot have had to carry out a significant amount of 'heavy lifting' with both the NHS and social care staff. Frontline staff both within the NHS and social care have a key role to play in enabling personalised care to become 'business as usual'. This will require a culture shift and an investment in resource, training and coaching to ensure these staff members become 'allies'. The NHS at a national, regional and local level will need to provide leadership around this culture change, developing an engagement plan for staff that will enable the scaling up of the programme.

IT systems

There is significant potential for IT systems to support delivery of personalised care, enabling the secure management of information and outcomes data. It is recommended that commissioners engage and implement IT systems with at least the functionality of those used in this pilot.

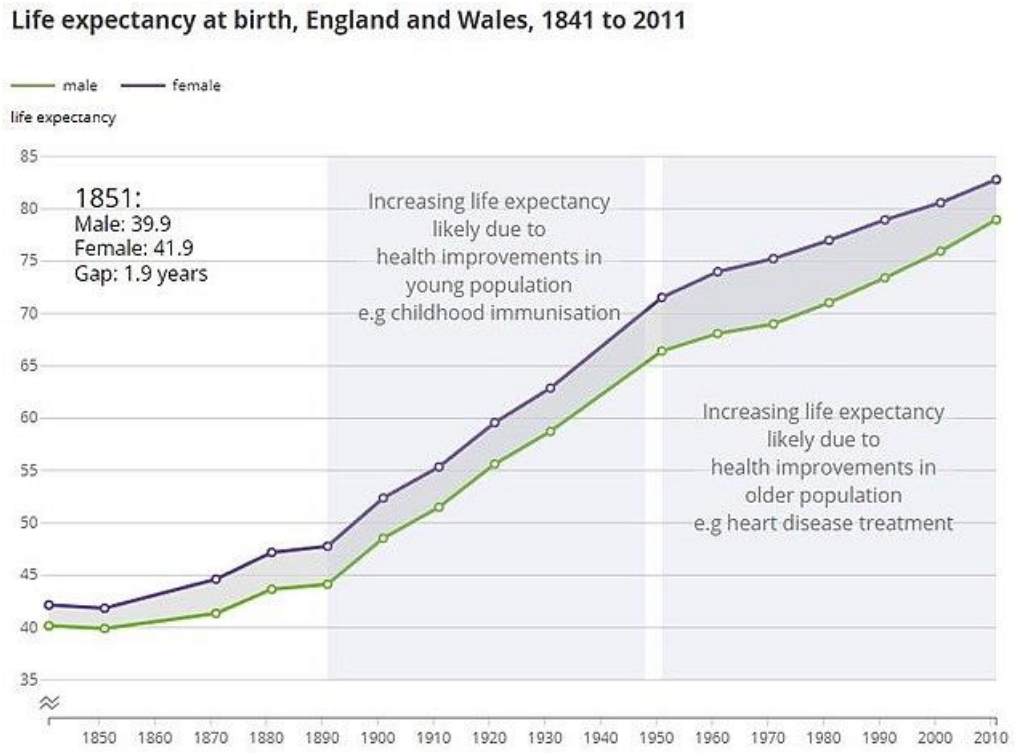
Business processes

The pilot has highlighted a number of important issues with business processes which are yet to be resolved. Some of these are highlighted in this report, but others, such as embedding processes at the frontline, integration beyond the planning process, and infrastructure and resource, will need to be addressed to roll out the model at scale.

Background and pilot context

Health and social care services in England are at a tipping point. Both sectors are facing unprecedented demands due to demographics, financial pressures, technological advances, and changing attitudes, with people wanting to be more in control of their health and wellbeing.

Population growth is anticipated across the spectrum, but particularly within those aged 65+, with this group expected to grow by 18% over coming years. This is in part due to better living conditions, but mainly due to improvements in health services and a reduction in mortality rates. The diagram below, taken from the recent King's Fund publication: *A vision for population health: towards a healthier future,* demonstrates:



People are living for longer with more complex health and care needs.[1] Of the population aged 65 or over, 15% are moderately or severely frail[2].

People with one or more long-term conditions now make up 30% of the population, account for 50% of all GP appointments and 64% of all outpatient appointments, and occupy 70% of hospital beds[3]. People with long-term and/or complex health conditions currently account for 70% of the cost of delivery of health services[4], yet those individuals benefitting from this spend are likely to spend less than 1% of their time in contact with health professionals. This reflects the commonly held view that up to 80% of the interventions that make a lasting impact on health improvement occur outside of the health sector.

[1] King's Fund (2012), Long-term conditions and multi-morbidity.

[2] Office for National Statistics (2017), Population estimates for the UK. London: ONS.
[3] Department of Health (2012), Long-term conditions compendium of information (third edition)
[4] Department of Health (2012), Long-term conditions compendium of information (third edition)

The understanding is that the broader impact on individual health related outcomes is achieved by considering the whole person through a wellbeing approach, of which healthcare services are just one element. Challenges around mental health services are also crucial within communities. Mental health has been a central factor to many of the individuals that we have worked with and their personal circumstances.

Simon Stevens' statement recognises the fact that harnessing the potential of patients as micro-commissioners of services could solve the dual issue of unsustainable demand on NHS services, and the funding burden. Integrated Personal Commissioning and personal health budgets are the key vehicles available to deliver the significant system change that is required, through targeted commissioning designed to meet outcomes.

"We stand on the cusp of a revolution in the role that patients – and also communities – will play in their own health care. Harnessing this renewable energy is potentially the make-it or break-it difference between the NHS being sustainable or not."

Simon Stevens,
Chief Executive of NHS England

Furthermore, there has been a shift in the expectations and demands of people using health and social care services – people want the same choice and control over their care as they have come to expect in every other area of their lives. A growing body of evidence now supports a more personalised approach, demonstrating that it can result in improved health and wellbeing, quality of care, and better use of resources.

A key drive was the transition from personal health budgets being a "right to have" into a mainstay of healthcare provision. Since the commencement of this pilot, the commitment from NHS England to rolling out personalised care has become much stronger.

By March 2019, NHS England expects that, unless there are exceptional circumstances, everyone living in their own home who is in receipt of NHS continuing healthcare funding will have a personal health budget. Therefore, all new people and funding approvals will default to personal health budgets. In East Lancashire, this equates to a significant increase to around 890 budgets if NHS England targets are to be met by March 2020, when NHS England has set a target for all CCGs to have personal health budgets in place for 0.1% and 0.2% of the population.

In recognition of the national context, and the potential for the health and social care markets in East Lancashire to function better, a pilot project for Personal Commissioning in East Lancashire was agreed in December 2016, between East Lancashire CCG, NHS England, The Calico Group, Alocura and My Life. This agreement followed two years of discussion and programme development around the establishment of a common purpose and agreed objectives for the pilot.

In July 2017, the pilot commenced delivery, with an operational team made up of staff from The Calico Group, My Life and Alocura. The overall ambition of the pilot project was to provide personalised care and support to a cohort of individuals in East Lancashire who are receiving NHS continuing healthcare, or have one or more long-term conditions.

The pilot was launched to focus on the development of a model that could deliver better outcomes through Integrated Personal Commissioning, with the achievement of personal health budgets at its core. Our aim was to increase participant choice and control over their care and support, allowing individuals to achieve lifestyle change, meet health and wellbeing outcomes, and feel more in control of their condition.

The pilot focuses on 10 objectives detailed in the following section. At the heart of each objective were these three guiding principles:

1. People with complex needs and their carers have a better quality of life, and can achieve the outcomes that are important to them and their families, through greater involvement in their care, and being able to design support around their needs and circumstances.
2. Prevention of crisis in people's lives that lead to unplanned hospital and institutional care by keeping them well, supporting self-management.
3. Better integration and quality of care, including better use, and family experience of, care.

"I have no support networks and I am fed up with being stuck inside all the time."

"Depressed, suicidal thoughts, feel like a burden on society."

"I don't have a life, I just exist."

"I feel like my fatigue rules my routine."

"I want to die."

"I worry that, if I take a turn, I may not come out of it."

Participant feedback, Pre-engagement BeWell Pilot

"I am really impressed with the service that I have received. It is the first time that we have felt listened to, and that someone has looked for other options available to meet my mother's needs and enable her to return home. You have kept my family and our wishes at the centre of everything that you have done."

BeWell participant

Delivery against pilot objectives

This section of the report provides an overview of our approach and performance against each agreed objective. This is provided along with some key lessons learned and recommendations for future delivery based on the outcomes outlined in the Memorandum of Understanding.

1.1. Pilot a way of working that is person-centred and enables personalised care and support plans to be developed which address the wider wellbeing of each individual to address their health issues.

A fundamental value of The Calico Group, shared across our partnership, is that individuals sit at the heart of the decisions we make. We deliver a co-production model where the individual is at the 'front and centre' of our thinking, and we seek to involve and engage them in discussions about the decisions we make that impact upon them.

Through the pilot, we have enabled a true person-centred approach, supporting individuals to take control of their care planning process. With each individual, a care plan was completed, looking at what was working well for the individual and building on this foundation. We were able to look at all aspects of the individuals' health and wellbeing, including their environment and existing support packages.

Individuals were encouraged to tell their story of how they got to where they are today, and we listened. We encouraged individuals to look ahead to their future, tell us what matters to them, share their hopes and dreams for the future, and consider what needed to be done to achieve their outcomes.

We talked about their health conditions and how this affected them. We talked about their historical treatment, and provided space, when required, for them to share frustration, concern and upset. We progressed the discussion to how we could support them, and deliver their wishes and preferences for treatment. Through personalisation, we have empowered individuals to develop their own action plans through identifying what mattered to them and how it could be achieved.

We were able to advocate on behalf of individuals, often translating the requirements to healthcare professionals. Where required, we have been able to work through risk management with professionals to ensure they are satisfied that the personalised care and support plan meets the health and social care requirements, but does so in a way that meets the needs of the individual.

Our approach has delivered a better outcome for the individual, their family, and the health and social care professionals. Plans are based around need, aspiration, development of general health and wellbeing, and delivery of long-term benefits that will reduce costs.

1.2. Develop an approach to individual integrated health and social care plans, including assessments and advocacy as necessary. This will involve identifying existing or proposed social care services, health inputs and social prescribing elements of the plan.

It is important to recognise the investment of effort that must go into the broader partnership working to enable Integrated Personal Commissioning and personal budgets to work. Health and social care are complex environments with long standing and traditional working patterns. It is not helpful to take an approach that seeks to disrupt individuals working within these environments. These staff need to be allies of the programme and ultimately will be the difference between success and failure.

Our approach was to allocate time from our senior managers to find these key individuals within the process, to positively engage them and convert them to allies. We worked hard to develop good working relationships with local health and social care colleagues, recognising that we would need to take the opportunity to them and, in doing so, acknowledging that they would not come to us. This process is one that needs to be sold to key individuals working within health and social care.

In terms of social care, the most successful intervention has been with those on the frontline who can see the benefits directly: the social workers themselves, where we have opened up a referral pathway and are working well in terms of plan approval. Engagement with senior level officers, unfortunately, has proved to be more elusive. In the main, this has been driven by the continuously changing landscape of local authorities driven by year-on-year budget reductions.

Additionally, the pilot is having to wrestle with the pricing and quality outcomes of the 'race to the bottom' that Local Authorities seem to have encouraged through priced-based procurement. We have had to work hard with the health authorities to highlight that this approach is unsustainable if the personalised care agenda is to succeed, something we believe the ELCCG understands.

We have spent time introducing the pilot and showcasing the achievable outcomes. We outlined a personalised, integrated approach, looking at the wider wellbeing of each individual. We made ourselves available and ensured that we were present in a variety of settings, enabling informal discussions with colleagues, whilst trying to develop confidence within the pilot.

Risk management and mitigation is a significant area of concern for professionals, particularly when discussions turn to non-clinical solutions.

We attend Integrated Neighbourhood Team meetings and, where possible, Multi-Disciplinary Team meetings to ensure that all eligible individuals were being considered for personal health budgets and/or integrated plans. With consent from the individual, we request assessments from health and social care, and liaise closely with professionals to ensure that all clinical and social needs are met within the plan, and that any risks are managed.

All of this is managed through a series of agreed processes leading up to approval of the care and support plan. A key component in the smooth operation of these processes is the role of the care and support planners. These roles and skills are equally as important as those of the PA, as they often have to 'unpick' complex family situations or circumstances that are causing problems for the individual, before the care and support planning can be kick started.

The ability of these people to be able to identify problems and bring solutions is critical to a positive outcome for the individual. In this document, we discuss the lack of capability and capacity in the PA market; the same can be said of the available supply of high-quality care and support planners.

"As a Trust, Lancashire Care Foundation Trust (LCFT) have begun introductory work with the ELCCG pilot team and, in recent months, we have been supporting the pilot via engagement with our community teams to embed the use of personal health budgets within them.
We are continuing with our engagement and roll out work with briefings that are due to take place next month, after which we will start to build the first personalised care and support plans."

Dawn Fearns, Integrated Discharge Team (IDT) Commissioning Manager, Lancashire Care Foundation Trust

1.3. Identify any gaps in required services and agree a procurement strategy to address these.

The major gap in service identified by our pilot project is the acute need for the layered provision of PAs in order to enable care at home. PAs are different to care assistants in the method of delivery and how they will spend their time with individuals. We anticipate at this stage that they will fall into three categories:

a. Level 1: These are roles for people looking for support with arranging and accompanying on activities, shopping and other more basic household tasks, companionship, meal prep and basic hygiene support (prompting).

b. Level 2: These are roles for people looking for the same support as in 'Level 1', as well as basic healthcare tasks, such as managing medication and changing dressings. These roles required more intensive social care tasks, such as moving (manual handling), assistance with meals (including feeding), changing pads, daily bathing, dressing and grooming.

c. Level 3: The most intensive roles where healthcare, such as tracheostomy care, palliative care, ventilation care and cannulisation, may also be required, in addition to some/all of the elements of 'Levels 1' and '2'.

At present, there is an immature market around providers for PAs, based around traditional 1-to-1 care and low pricing. Whilst we think that those operating in domiciliary care markets are well placed to enter the market, it is clear that they will need significant support to achieve the required standard.

A framework for a functioning marketplace made up of accredited and appropriate providers will need to be established. Working with East Lancashire CCG and local colleges, we have already started this in East Lancashire. Other areas seeking to deliver personal health budgets will need to consider how they will manage procurement around this new market.

Based on information from our pilot, we anticipate that, on average, a person with "specialist" or "targeted" needs, with a personal health budget, will require 4.8 PAs. For the other 70% of the population, we estimate that this will more likely be 1.5 PAs.

In East Lancashire, these roles do not currently exist in the numbers that are required and will have to be established to facilitate the growth in personal commissioning. For the target of 890 approved personal health budgets, we anticipate that the workforce requirement for PAs will be circa 4,000 individuals across the levels outlined above.

The development of the PA workforce will require a concerted, multi-partnered approach, in order to establish a workforce that demonstrates the right behaviours, and has the quality and technical knowledge required. The added benefit of this approach is to ensure that PAs at whichever level always have the headroom to progress into a higher/better remunerated position. We anticipate the following actions:

1. **Pre-workforce engagement** – It is important that individuals coming to the workforce are motivated with the right values and behaviours. We promote the development of a workforce that is caring and competent at all three levels. The position available should be well remunerated and, as such, we should be attracting the very best. To ensure this is achieved, we recommend a Pathways 2 Employment model (developed by My Life) which offers a pre-engagement opportunity to ensure that the individuals we seek to recruit meet not only the technical ability, but are also the types of individuals that we would want caring for our mums, dads, brothers and sisters.

2. **Recruitment** – All recruitment processes led by participating organisations should include the individuals receiving care (if possible) and the family. The decision to recruit a PA should be joint, with the individual and family being given significant opportunity to influence.

3. **Continuous Professional Development** – The framework for procurement should align with a programme of continuous professional development that is available to all providers, delivered in partnership with a suitably qualified further education partner. The annual framework should be developed in consultation with PA providers and clinicians, and should be reviewed quarterly based on need from the market. This should be dynamic in nature.

4. **Ongoing investment in PAs** – Organisations employing PAs should use their Apprenticeship Levy to invest in their staff, supporting them to move up the three levels outlined above. The overall objective of the workforce development plan should be one of progression that enables continuous entry into 'Level 1' positions.

1.4. Assess the outcomes and social values/cost benefit that flow from this approach. This may include identified health benefits from 'free-to-use' universal services, as well as social care funded services.

1.5. Also assess the cost of existing health inputs insofar as data allows and analyse local supplier market positioning. This will generate the opportunities to improve services and realise potential efficiencies.

The outcomes relating to the pilot project will be formally reviewed on the 12-month anniversary of the project in July 2019. Our methodology has been to collect data at the start, and then every three months as the personal health budget progresses, and provide output reporting through the utilisation of the POET qualitative and social profit quantitative tools.

Social profit is the combination of three established methodologies: consideration of social return on investment; consideration of cost/benefit analysis; and consideration of the local economic effect of service inputs. Our pilot combines this quantitative analysis with the qualitative output of the POET system to produce a whole person outcome map. Not only are we able to tell the story of change, but we are also able, through social profit, to financially quantify it.

The data collection we have achieved is limited due to the number of returns (22 individuals) at this stage of reporting. However, it does allow us to assess the number of interactions with health services by individuals participating. Using the Global Values Exchange, we have attributed an estimated value to each interaction. In July 2019, we will be able to demonstrate the impact on service use and, if the model is delivering positive wellbeing outcomes, the estimated net cost benefit.

At this stage of reporting, we can indicate the baseline position and, based on our discussions with individual participants, we can forecast the likely outcomes we anticipate that we will achieve.

As a starting point for our evaluation, we asked individuals to provide a statement of how they felt at that point in time. This was done ahead of accessing the programme, along with asking them to self-assess their health. On average, out of a score of 100, individuals scored themselves at 29. Anecdotally, through discussion with our staff and the individuals participating in programme, we would anticipate a 15-20% improvement in this score by July 2019.

Based on the clients who we are currently working with, and survey results received to date, the most significant improvement has been in their ability to be a part of their local community (+48%), with their emotional wellbeing being improved by 40%.

Overall quality of life improved by 39%, choice and control over everyday things by 36%, and ability to live independently by 34%. Self-esteem improved by 33%, and physical health by 30%.

The most positive existing aspect of their lives that clients told us about was in their relationships with family and friends, but this still showed a 20% improvement according to the survey.

We have been able to work through a limited list of cost areas that apply to individuals benefitting from the service to date. At this early stage, we have been able to identify cashable savings, in the main linked to the provision of emergency and/or crisis services. At present, the individuals we are working with report a 67% reduction in use of health and clinical services. The reduction in emergency and crisis services is even greater at 76%. Overall, at present, we are able to demonstrate an 84% real cost saving to the NHS based on our programme activity.

At present, at a headline position, we forecast that the social value attributable to the pilot for the 22 individuals involved is £430,000. This figure relates to the benefit felt by participants as a result of improvement in wellbeing and lifestyle improvements.

We anticipate, based on the small sample of 22 participants, an overall cost saving to the NHS of £1,232, using actual unit cost data provided to us by local clinicians. This reflects a cost saving of 84% by the end of year 1.

Our initial workings around this are provided at appendix 2.

This figure will be further developed and scrutinised over the reporting period to September 2019, with a full social profit statement produced as part of the final report at that stage. A key challenge for us at this stage of reporting is that we require participants to recall and disclose their health service usage for the previous 12 months. The data would have greater integrity if it was possible to draw direct from health service records.

1.6. Demonstrate an approach that can develop a market which allows patient choice and a software model that can manage personal health budgets.

When the pilot was established, we envisaged that the goods and services market would be predominantly driven by component parts of clinical services that needed to be procured from suppliers. We sought to identify and categorise key areas of procurement to establish a functioning market place where individuals, with support from professionals, would have choice over the goods and services they received.

Secondary to this is our ambition to identify and categorise the market place, enabling standardisation of key items purchased and, by doing so, put a significant downward pressure on the supply cost of these items. By achieving this, we hypothesised that we would be able to deliver efficiency through monetary savings to the NHS.

As the pilot progressed, two things became apparent:

1. Much of the supply of goods and services contracted by the NHS is done through block contracting arrangements managed at scale. Interrupting these arrangements is a significant task that is beyond the scope of the pilot.

2. Up to 80% of the market requirement in the envisaged new personalised care market is likely to be PAs. This represents a significant cultural change to the way in which services are delivered. From our experience, we know that the market for the supply of PAs does not exist and, as such, will need to be developed.

The creation of a new marketplace will be an important step to securing the success of a new personalised care market: without PAs, it is unlikely that efforts towards personalisation would be successful. The development of the

framework or, more accurately, partnership with providers enables us to run a procurement process that secures numerous organisations from a broad range of delivery backgrounds. This is a task that The Calico Group and Alocura are moving forward with in the New Year, with the support of the CCG.

The immaturity of this market is a benefit with respect to creating choice, but also presents a further opportunity for market shaping. Organisations wishing to participate in the market can, as part of the procurement process, be coalesced to behave and perform in ways that best meet the needs of individuals procuring from the framework. This is a unique opportunity to set a higher standard of expectation from providers, with better quality and true customer participation.

In addition to the healthcare services that will require procurement, our pilot has also introduced to the marketplace catalogue services that are universally free. In the main, these are the services that link an individual to lifestyle improvement and better wellbeing outcomes. The introduction of these services to the marketplace is important in that it empowers our individuals, providing opportunities for support that move them beyond their health condition.

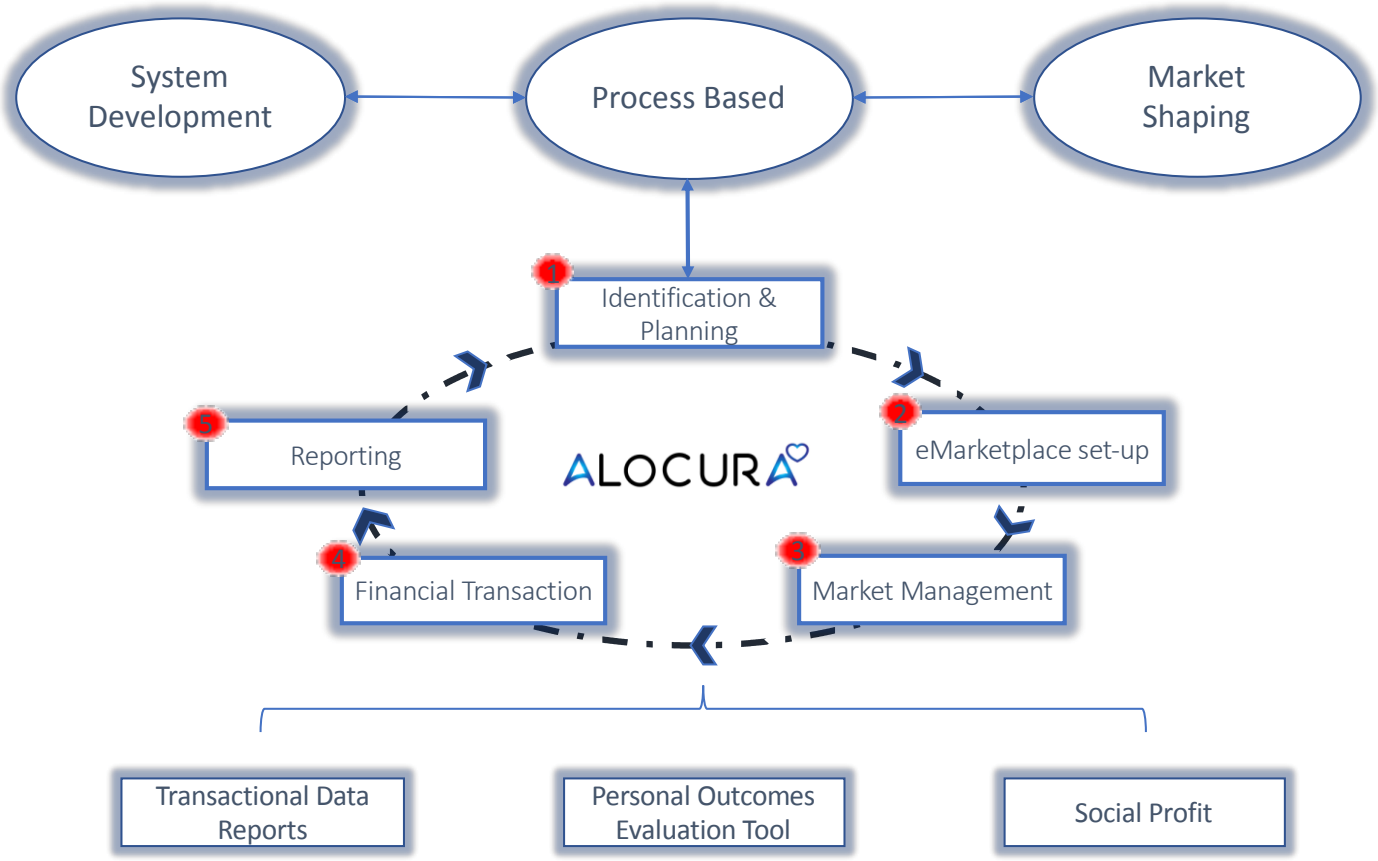
This supports the conclusion in the King's Fund report *A vision for population health: towards a healthier future*, where the authors state: *'The NHS has a critical role to play but these challenges cannot be met by the health and social care system alone; a much broader approach that pays much more attention to the wider determinants of health and the role of people and communities is required.'*

Our approach demonstrates that choice within personalisation can be achieved in the majority of cases, but there is work to do beyond the scope of the pilot in relation to services that are block procured. For the individual in receipt of the personal budget, the key thing is a sense of purpose and feeling of control over their care package.

1.7. Deliver a set of standardised processes and systems which can support efficient roll out of personal health budgets in East Lancashire and the North West.

Alocura has an established and deep knowledge of complex market set-up and transactional processes; they understand both the importance of systems and the service 'wrap' that needs to be in place to ensure that those systems are able to provide the commercial outcomes required. Alocura utilises the 'shop4support' system and has embarked upon enhancements to this system in care and support planning, and the rostering of PAs.

We cannot emphasis enough how important it is to ensure that the system supports activities 'at scale' in an efficient and effective manner. These processes could be standardised by NHS England and utilised as guidance as part of the role of our Personal Commissioning as the agenda moves forward. These process maps are available upon request.

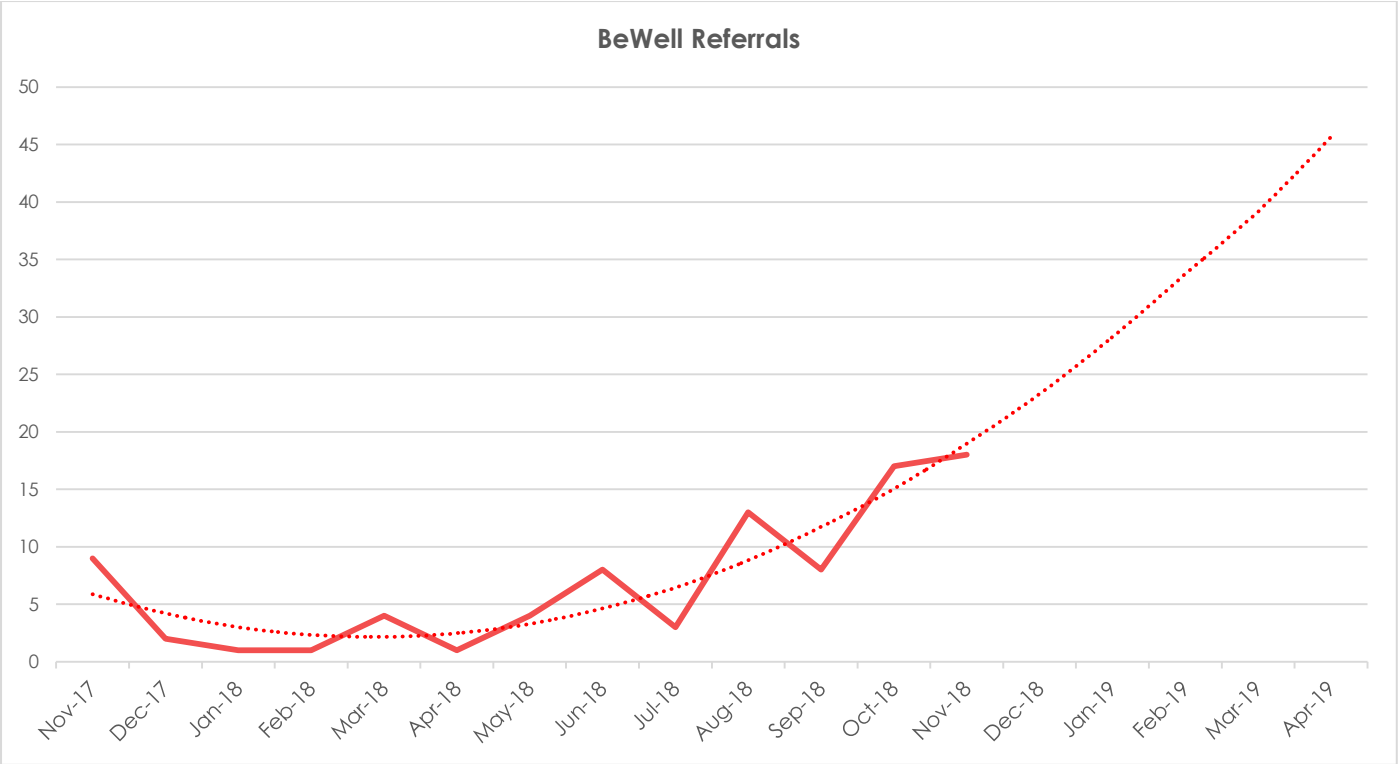


System and Process Model

1.8. Demonstrate an approach that allows an increase towards the ELCCG target of 450 and 890 personal health budgets by 2020.

Our target was to identify 50 individuals that would benefit from a personal health budget who would be provided with a personalised care plan. Of the 50 individuals we were targeted to work with, we anticipated that 60% (30 individuals) would achieve a personal health budget.

Referrals into our programme were initially slow due to the requirement to have to identify and open up referral pathways and onboard referral partners. As the graph below demonstrates, we opened up the referral pathways and, in the last quarter, referrals to the programme have increased significantly. The dotted trend line indicates the forecasted growth in referrals through to April; at our current level of growth, we would anticipate achieving 45 referrals per month by April 2019.



Through our pilot programme, we have achieved, as of December 2018, 81 individuals referred and either assessed or currently undergoing assessment. Of these numbers, we have identified that only 19 cases (15%) were not eligible, and these individuals have been signposted into other services.

Within the calendar year, we anticipate therefore that 62 individuals will have moved through our process and will have either had a personal health budget approved or be some way towards approval. We have focused on addressing individuals with either more complex or longer-term health issues; therefore, the average budget value of live cases is £72k. A review of our forward pipeline suggests that this will increase to an average figure of £134k.

Referrals to our programme commenced with regularity in July 2018 after an initial period of engagement with key teams. Intelligence from working with Integrated Neighbourhoods Teams, the Lancashire and West Midlands CSU, GPs, Adult Social Services, and other referrers, gives us the confidence to assert that the targets outlined in the objective, and the new target of 1,300, are eminently achievable with the right levels of investment.

1.9. Determine the extent to which the model for the project can be financially self-sustaining moving forward. Provide initial economic modelling for future activity.

The pilot has established that there are three areas of cost that relate to the delivery of a successful personal health budget through our model. Firstly, the cost of advocacy; secondly, the cost of the market place transaction; and thirdly, the overall cost of the care. These costs parallel those that can be found in existing arrangements around block contracting.

Firstly, there is the cost associated with advocacy and development of a suitable health and social care and support plan. Funding is required to assess suitability for a personal health budget, and to develop a detailed care plan assessment. Based on evidence from the pilot, we anticipate that the unit cost for this work is £1,295 (plus VAT) based on meeting the individual, discussing needs, reviewing and considering prior notes, and development of the care and support plan.

We think that it is prudent to also allow for reviews which would cost £195 (plus VAT). We think that this should be at least annually, but maybe more frequently dependent on complexity. This can be agreed as part of the care

planning approach. This process of review also provides the opportunity for monitoring of outcomes that supports the assessment of impact of interventions.

There is then the cost associated with the personal health budget. There is a wide variation in the scale of personal health budgets dependent on the outcome. Within our pilot programme, the smallest is £13,331, whilst the largest is £144,144. The average current personal health budget within our pilot scheme is circa £72,000, but we expect this to rise to £134,000 over coming months given the cases we are working through in our pipeline.

The third area of cost that is associated with the programme relates to the management of the transaction and the marketplace. The pilot has been transacted at 5% of the budget costs, which is competitive with the market. However, this broad-brush approach is not suitable for ongoing use, and a revised pricing structure will be implemented post pilot which works on actual costs, reducing the cost to funders of the higher value case management. We accept that this is a developing area.

The pilot has raised a number of questions around how our model, or indeed any model, might be rolled out at scale.

The cost of care planning, advocacy and marketplace transactions are costs that are essential in respect of moving forward the personalised care agenda. Healthcare and social care are complex areas of activity, and we know that achieving a budget without support would have been unachievable.

Our programme also bears out the developing thinking that solutions will not always be found in traditional delivery, or in clinical settings. Approximately 80% of the budgets that we have seen approved support the delivery through PAs; traditional social care models operate on a '1-to-1' basis; in our cases, this is '5-to-1' and, in some instances, more. These are roles performed by individuals in the home setting, often linked to wellbeing outcomes rather than health or social care.

At the start of the pilot programme, a target of 890 personal health budgets by 2020 was established. Assuming that the minimum target of 890 is achieved in East Lancashire, and utilising our average outcome figures, we provide the following information[5]:

a. Based on the average conversion rate, to achieve 890 successful personal health budgets, we estimate that 1,046 individuals would require assessment, care planning and advocacy.

b. Based on the average personal health budget values for "specialist" and "targeted" of £134,000 and a personal health budget average rate of £25,000 for the remaining 65%, we would anticipate a budget expenditure to facilitate the whole population of £56.2 million.

A figure of 890 personal health budgets is sought in Lancashire by 2020. To achieve this, we anticipate that £56.2 million would need to be freed up from existing resources to support care plan outputs.

The transition to this model of delivery, over a period of time, could deliver a cost saving if funds are reallocated to this new model of care. The risk of not changing the care model is that, rather than delivering efficiency and ultimately savings to the healthcare budget, personal health budgets will increase costs to healthcare services.

The model that we have established and developed has the potential to be self-sustaining in the long-term. This assertion comes with the following caveats:

[5] Information provided is based on pilot data with a population of 56 cases. The information is provided as guidance only as the margin for error is significant.

1. Our pilot has delivered at a relatively small scale. The financial impact of our work has been absorbed within existing budgets, which is manageable on a small scale, but not necessarily on a larger scale. Along with the imperative to 'scale-up' will be the necessity to restructure existing budgets, disaggregate block contracts, and understand the need to invest in good outcomes to realise the long-term savings that will come through improved wellbeing. Fundamentally, the NHS will need to embrace the new model of service delivery and adopt a new spend profile that may mean that some of its traditional services and activities will reduce in scale or may cease to exist. This is necessary to release the scale of funding required to achieve critical mass.

2. The model requires elements of spend on advocacy and marketplace management that are not transparent in current models of delivery. In the long-term, these additional costs will be outweighed by the efficiency savings generated. In the short-term, these costs will be an additional burden.

Information from the Lancashire and South Cumbria Health and Wellbeing Board indicated that they anticipated savings of 18% through the delivery of personal health budgets. This is a figure that our pilot could support in the long-term based on our outcome projections.

Based on our assessment, we anticipate the scale of the financial saving that could be achieved after advocacy and marketplace costs would be in the region of £8.34 million per annum. This does not include any assumptions on marketplace savings through better alignment of category management and downward marketplace pressure on price point.

1.10. Stimulate the cultural change with health professionals to support personalisation, to utilise asset based care and support planning, and to understand the wider determinants of health.

Knowledge of personalisation is starting to trickle down NHS organisations, but there is still a sense that this is something that staff are being told to do, rather than wanting to achieve - an important difference. A key element of the broader success of personalisation in future years will be built on the extent to which staff within the NHS feel ownership over this process, and empowered to be part of it. The correct balance around ownership and empowerment will come from leadership within local infrastructures.

A challenge for our pilot has been the acceptance of healthcare professionals that personalisation is achievable and may lead to improved outcomes for the individual. Our experience has been that healthcare professionals are entirely committed to their patients, but may not always be open to challenge or consideration of the importance of non-clinical interventions.

Early within our pilot, we took the decision to seek to meet with healthcare providers at a local and regional level to really engage them in our work and what we wanted to achieve. We recognised that this would not be easy and resourced our approach to enable multiple approaches over a period of time. We were persistent and this paid off. We have worked with healthcare professionals at a number of levels and, during the delivery of our pilot programme, we have seen a shift in perception. We acknowledge that the teams that we are actively engaged with have welcomed a change once they could see demonstrable outcomes.

In order to move people along the scale of acceptance, there are two key things that we have found must be demonstrated:

1. That the work we have done has made a demonstrable change to the individuals, their lifestyles and their health related outcomes. This must be demonstrated through a case study type approach and reference how the impact is replicable and scalable.

2. The approach to partnership must allow the healthcare professional to manage risk. At the centre of every discussion we have been involved with has been a desire to do the right thing for the individual involved. If the risks are discussed and assessed, and the healthcare professional feels that they are managed, they will participate.

Key learning points

The pilot has enabled us as a partnership to explore the field of personalised commissioning, learning a number of important lessons and posing some equally important questions that require further consideration.

Our thoughts and findings have been gathered around the following three key objectives from the Memorandum of Understanding that we have used as a guiding document for this pilot.

1. People with complex needs and their carers have better quality of life and can achieve the outcomes that are important to them and their families through greater involvement in their care, and being able to design support around their needs and circumstances.

The pilot has demonstrated that supporting people with complex needs to achieve a better quality of life is not only possible, but is necessary to improve health, care and support related outcomes. Our pilot has demonstrated the pivotal role that placing the individual at the centre makes, and how this delivers improved outcomes for less investment. The individuals participating are happier and healthier, reporting better standards of living in every case.

A significant proportion of the individuals that we met felt that they were not achieving their desired outcomes and also that they did not have any quality of life; this was highlighted when they completed the health questionnaires and POET survey at the start of the process. Prior to engagement, individuals reported that they often did not feel listened to or given a choice to be involved in the decision making around their care or what mattered to them.

Completing the plans with individuals and their families enabled individuals to express what was important to them and how best to support them, and gave them an opportunity to identify what was working and what could be changed to improve their outcomes, and also to look at long-term goals and aspirations.

Our key learning is outlined below:

Being person centred

Delivery should seek to work in partnership, through advocacy, with the individual, placing them at the centre of the process, and consulting with them at every stage. The approach to delivering a successful personal health budget should also involve family and friends in the development of a solution. The process should ensure that the needs and aspiration of the individual are met, and avoid delivering care solutions that fit only the needs of the organisations.

The importance of organisations working together on a locality basis cannot be under-estimated. A very high percentage of our participants reported fragmented approaches derived from organisations working in silos. This impacts on their health.

Placed based approach

The care and support planning phase needs to consider and include much more than just health related outcomes. Advocates, when developing their care and support plan in advance of seeking approval for a personal health budget, should give full consideration to asset based community development, making the most of the universally free services that make a significant impact to the overall wellbeing of the individual. Lifestyle improvement is the major factor in improving health.

Self-care approach

Individuals are more likely to get better, or at least arrest decline, by being at home in familiar surroundings with familiar people. Personalised care should promote this with care requirements provided in this setting.

To enable this, individuals need a new model of care built around the requirement for PAs. In turn, this will require the NHS to free up resources in order to fund these requirements.

2. Prevention of crisis in people's lives that lead to unplanned hospital and institutional care by keeping them well, supporting in self-management.

Individuals tend to hit crisis situations when health and care services fail to address the core issues in their life. The solution is often not a health-related intervention, the answer more likely being found in the wider determinants of health – housing, familial reconnection, and reducing social isolation.

The cohort of individuals that we have worked and co-produced plans with have previously been at, or were reaching, crisis point. In almost all cases, this led to recurring hospital admittances and even suicide attempts.

Most individuals have reported that this was due to the fact that nothing had changed between each episode; they reach crisis point, are admitted to hospital, and then discharged back into the same situation, without having any input, choice or control over their care - a revolving door that adds pressure to their situation.

These individuals were difficult to engage initially, as they had no confidence in services delivering what they said they would and expected to be "let down" again. They also had limited knowledge of what different services were available, other than what they had always received. They had not previously been involved in the planning process and they struggled to see what a personalised package of care could look like.

Even though these plans took much longer to write, as additional support was required initially to re-engage the individuals, the amount of care and funding needed to meet the individuals' needs was often low. The impact of the intervention was high on the individual and the reduction in service use. We identified that a key element associated with individuals reaching crisis point was social isolation; no or limited family, friends or community involvement, leading to loneliness, poor management of their health conditions and deteriorating mental health.

By re-connecting individuals with their communities and matching them with PAs, they were able to develop their self-esteem and confidence, and become independent in self-managing their health conditions, significantly reducing the amount of time spent in hospital.

3. Better integration and quality of care, including better use, and family experience of, care.

The pilot clearly indicates the significant impact on the individual of getting the integration of health and social care packages wrong. Integration, particularly when the individual and their families are involved, presents an opportunity to get the package right. A focus on overall affordability of the care package is also important; consideration of hourly rates is less so as the overall efficiency should deliver a better care and financial outcome.

In a number of instances, the pilot has demonstrated that, whilst some individuals had packages of care in place, these arrangements were not meeting the individual's needs. We experienced multiple examples where it was evident that the package of care was not achieving the desired health or social outcomes.

Utilisation of the POET tool and the Social Profit Calculator health questionnaire allowed us to develop an understanding that lack of good quality care was a key issue in East Lancashire. Experience of care providers is variable. Individuals reported experiences of care providers, ranging from numerous carers "calling in" within the day, to a 24-hour carer who lived in but never took the individual out of the house.

Some carers focussed on social needs, some on health needs, but none integrated the service and focused on both. Many individuals were unhappy with their care providers or felt that they were unable to meet all of their needs in a personalised, integrated way.

Individuals often felt that the care provided was driven by the funding rather than the needs of the individual. This is understandable given the restrictive funding models currently in operation that force a limited service and risks a race to the bottom. To make a lasting, sustainable impact on individuals, this cannot be the case moving forward.

Commissioners should focus on the affordability of the overall package of care rather than the hourly rate of each service provision.

The option of having a PA or team of PAs who could support both health and social needs, and who would be matched to the individual through mutual interests, was something that appealed to most of the individuals and their families.

This was achievable through the delivery of the Pathways 2 Employment course, which recruited local people to deliver the care. Individuals and advocates were invited to attend the course, enabling them to find out more about the PAs, and to identify any potential matches.

All of the plans that have been written have included PAs - this demonstrates the growing need for integration and personalisation.

Our model

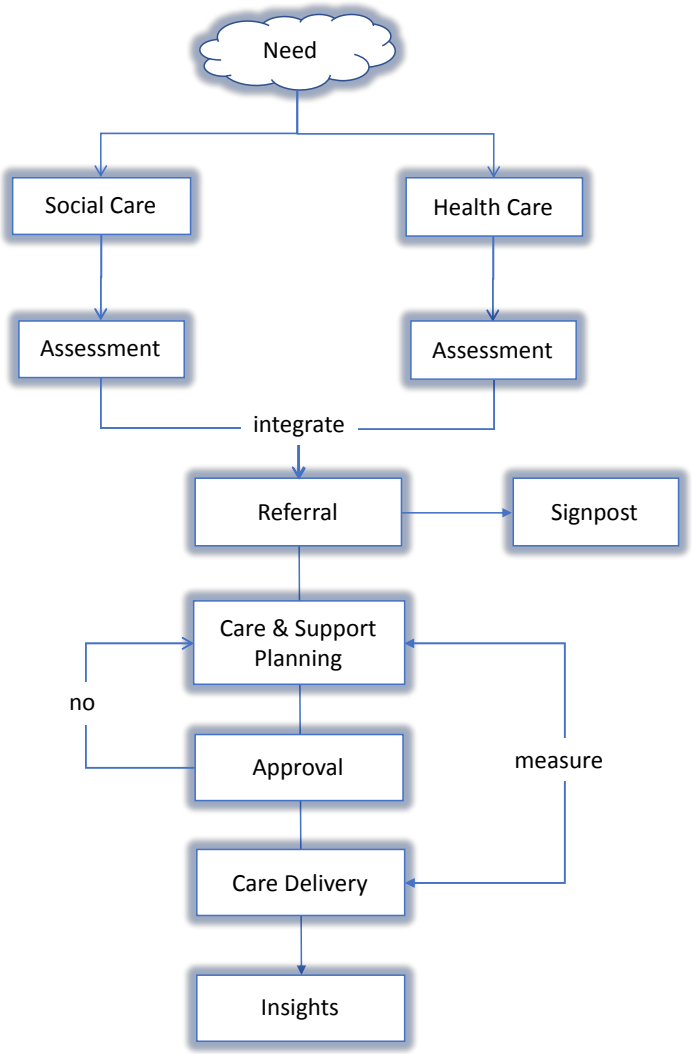
The detail of our delivery model has the potential to be complex, as demonstrated by this diagram.

It requires an understanding of how the programme tracks through identification of individuals, support and assessment, integrated care and support planning, development of health and support offer, categorisation, and authorisation for funding, procurement, and service delivery.

This complexity is multiplied by the fact that it requires a dual conversation with health and social care professionals that often operate in different ways.

In its simplest of forms, our model engages individuals that have complex needs, provides a space for a discussion around their needs and aspirations, establishes a care and support plan that focuses on health and lifestyle needs, and then seeks authorisation to deliver.

There are some key stages that require further unpacking in order to share good practice that are outlined in the next section.

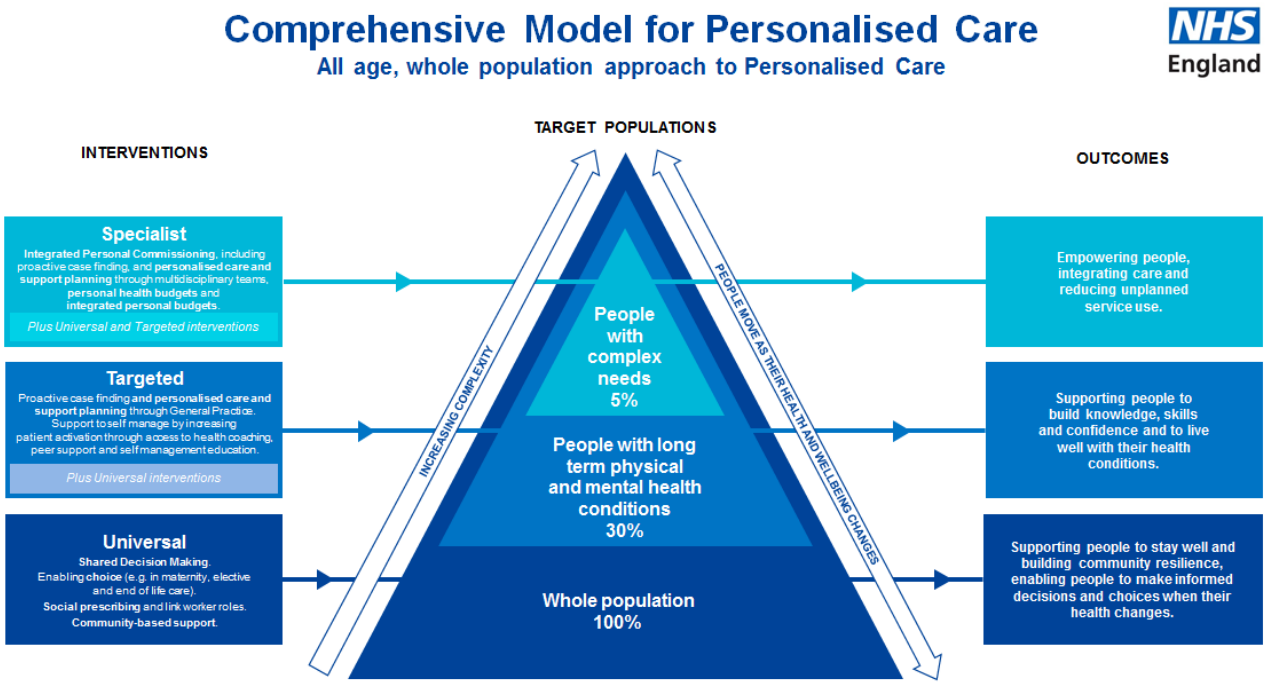


Referral

Adults who are eligible for NHS Continuing Healthcare (CHC) funding, and children in receipt of continuing care, have had a legal right to have a personal health budget since October 2014. By April 2019, NHS England expects that, unless there are exceptional circumstances, everyone living in their own home who is in receipt of NHS CHC funding will have a personal health budget.

All areas across England are expected to offer personal health budgets to additional groups of people, based on local need, including people with a learning disability and/or autism. Decisions about who can have a personal health budget outside of NHS CHC are made by local CCGs who are responsible for paying and planning for most local health services. Every CCG should have information made publicly available about who is able to access one locally.

During the course of the pilot, we have worked with people across the range of complexity demonstrated by the model. Our pilot has found that we are able to generate the most benefit by servicing the top 30% recognised as "targeted" and "specialist" that have moderate to high levels of complexity. NHS England recently published the following graphic to illustrate its all-age, whole-population approach to delivering personalised care.



Source: NHS England

The referral pathways we anticipated at the start of our programme of activity were through GPs and mental health services. In reality, for individuals requiring "targeted" and "specialist care", these were not the pathways where we found the individuals that stand to benefit from our support the most. The individuals identified as benefitting most from our programme are found within the Commissioning Support Unit and the Integrated Neighbourhood Teams. In addition, we continue to work to open up new referral routes, an example being the mental health team at the Lancashire Care Foundation Trust.

As we move forward, we expect more referral pathways to open up as the model gains traction, and we are able to embed the process within the day-to-day activities of frontline staff. There is one point of caution. Within the pilot, we have developed excellent relationships with practitioners within the Midlands and Lancashire CSU. However, engagement with the business management team within the CSU has provided a number of challenges which we are managing to work through but require further resolution. It has not affected our approach, but we believe our pilot has challenged their current business model and resulted in a lack of engagement, leading to delays in referrals to the pilot.

Assessment process

The process for assessing an individual for a personal health budget is relatively straightforward, assuming that the required information is available and that the information sharing agreements are in place between the relevant organisations. The key challenge around the assessment phase is to ensure that individuals understand the process of intervention, the timescales for approval, where they are within the process, and that ultimately an assessment may not lead to an approved personal health budget.

Early on in our pilot, we recognised that individuals were often in distress at the point of consideration for a personal health budget, and that our advocates had an important role to play in managing expectations. Without this approach, the process of securing a personal health budget can add an additional burden of concern to their condition.

We also recognise that approximately 18% of the individuals that we see through the referral process will not be eligible for a long-term personal health budget and, as such, would exit the pilot programme. These individuals have come to our attention because they require support; our partnership recognised the importance of this interaction and put in place signposting arrangements to other services, which in many ways is the 'big win' for the health authorities, achieving excellent wellbeing outcomes, but without the mainstream health services.

In addition to this, we would recommend the development of what we have termed a short-term personal health approach, whereby individuals receive support for up to six months to help them move beyond crisis. This support would generally focus on short-term lifestyle and wellbeing adjustments. Calico Enterprise has provided a separate paper detailing a proposed model for the delivery of this service.

Authorisation for funding

At a local level, the process for accessing funding when approval is achieved is not clear.

As has been explored more fully earlier in this report, the outcome of personalisation is a marked shift from traditional methods of healthcare to personalised care within the home, usually through PAs. The funding for these changes to delivery is not currently identified.

Within the pilot, East Lancashire CCG has shown itself to be both creative and innovative in its approach to funding, but this approach may not be sustainable. Without specific funding, resource and infrastructure within the NHS to manage personal health budgets, then in the long-term it is likely that cases will become backlogged and the proposition unsustainable.

In the long-term, we do not anticipate a need for extra funding to be provided, as the system should have enough funding within to facilitate. The key issue for the NHS is the short-term, where it is likely a transitional period will be required. In this period, it is likely that current funding mechanisms will not easily be able to transition from traditional areas of spend to facilitate the likely requirements of personalised care. In short, the programme of personalisation will place an additional cost that will need to be funded.

The Better Care Fund could provide a short-term solution. The NHS England website describes the fund as *'a programme spanning both the NHS and local government which seeks to join-up health and care services, so that people can manage their own health and wellbeing, and live independently in their communities for as long as possible'.*

The fund is established to improve the lives of society's most vulnerable people, placing them in the middle of their care and support, and providing them with integrated health and social care services, resulting in an improved

experience and better quality of life. The purpose of the fund mirrors the purpose of our programme, and our outcomes are demonstrations of what the fund could achieve. Utilisation of this fund needs further consideration.

It is also worth considering the broader agenda of funding that is designed to help individuals. Throughout the pilot, we have managed the challenges around the integration of health and social care funding. In addition, we have begun to explore the potential for bringing together other funding streams, including Access to Work funding and Disabled Facilities Grants. There will of course be other funding streams that could form part of the picture if we are considering a whole-person approach. If the intention is to improve the patients' health-related outcomes through the delivery of lifestyle change outcomes, then these items should be included in care plans.

For the individual around which this all should revolve, they care little about who ultimately pays – only that the package of care (health and support) that they require is in place and is functioning. This isn't currently the case, and more work is required for commissioning bodies to strengthen relationships that ultimately lead to joint commissioning models. There are no current local joint panel arrangements in place that facilitate a discussion around multi-partner funding. This is required if personalised care is to work at scale.

Procurement

A key area of concern for our pilot steering group was the transparency of transaction where a personal health budget is secured. At present, an individual securing a personal health budget can receive the funds associated with their care direct to their own personal bank account. Healthcare services have no visibility of how that money is spent or the process adopted to procure services that fall outside those delivered by the NHS through their block procurement arrangements.

Alocura, as a key partner within our pilot, was able to rise to the challenge of solving this area of concern. Working with Shop4Support, we have established an IT system that allows complete transparency of both aspects of the transaction – from the funder into the client account, and from the client account to the provider.

This transactional transparency ensures that the funding provided can be traced and easily audited against the spend areas that were intended, and also enables us as part of our outcomes assessment to understand the financial dimension of any improvements that we are making, through the granular nature of management information produced.

Monitoring and assessment

Securing a personal health budget is the starting point of a new method of delivery. It is important to consider how new processes build in measures for checking that outcomes are being delivered as required, and to assess the impact of the care package on mainstream health services.

On the latter, this fulfils two important functions. It ensures that the individual has the care that they need at that point in time. Secondary to this, and assuming that the outcome is a general improvement in health condition, it should provide the platform for agreement to step-down interventions. In this secondary area, we would expect to see the potential for cost savings against individual plans.

To successfully achieve this element of the process, it is critical to have an integrated IT system that enables information and data to be captured in real time and held against the individual.

In our pilot phase, we have utilised the system developed and managed by Alocura, which has proved to have the capability to handle all elements of the process, as well as the required resilience for future development.

Appendix 1: Case Studies

NB: Names in the following case studies have been changed to preserve anonymity.

Case Study A:

Robert is a wonderful 72-year-old gentleman from Nelson, East Lancashire, with a huge character. Many people would describe him as a 'typical' northern man of his era who has worked all of his life to support his family.

He would describe his role as the 'breadwinner' for the family and loved his job as a Civil Engineer for Lancashire County Council. Robert is a proud man and has been married for 52 years. He has three children and several grandchildren; however, due to his illness, he has been disengaged from his family for the last couple of years.

Robert was referred to the pilot project in the summer of 2018 as part of the Court of Protection proceedings and is residing in a specialist nursing home subject to Deprivation of Liberties (DoLs), due to his severe clinical needs and behaviour relating to years of uncontrolled diabetes.

He had been in and out of hospital and various nursing home settings due to the complexities of his needs. After various placements were deemed unsuitable, he was moved to a specialist nursing home; however, this was 30 miles away from his own home. Robert became frustrated with not living close to his family and the situation, which was expressed through his volatile behaviour. He was clear he wanted to return home or at least in the community where he had lived all his life; however, the challenge was to see if his needs could be met within his community.

We visited him within the nursing home and we explained the process of doing a support plan that would look at exploring moving him back home to his own community using a personal health budget. Although he was cynical, he agreed to explore the options.

The support plan process started and many people were supported to contribute to the plan, including the clinical team around him, his current team at the nursing home, and Robert himself. He was very clear he wanted to have contact with his wife, whom he hadn't seen since he first went to the nursing home a couple of years ago. We explored if this would be possible and, at first, spoke to his son-in-law, daughter and wife.

It was discovered that Robert's wife really wanted to see him but had been unable to for reasons beyond her control. We reunited Robert with his wife and arranged on a regular basis for them to meet up within the home. During the drive picking his wife up to take him to the home, we discovered a lot about Robert's working life, his role as a father, and all the family dynamics. This enabled us to form a picture of who he was as a person, as well as understanding his clinical needs, and how best he could be supported.

We put together an interim support plan that would enable Robert to come out of his nursing home for the day, supported by the My Life care team at their base in Standish for a day at a time. He would be supported by an experienced staff team and an RGN, ensuring his clinical needs could be met, and an assessment could take place. If each day proved successful, we would look at him staying overnight within the My Life holiday let chalets with full 2-1 support and clinical oversight.

To date, his day support has been very successful, and he has been clinically stable. He has participated in various opportunities, from the wood workshop to taking part in horticulture and meeting the animals on the farm. Robert has enjoyed his time at My Life, and we are looking at building up his overnight stays to confirm suitability for support in the community.

If this proves successful, we will work with Robert to assess housing options. Having the Calico Homes housing team involved has enabled us to support him and his wife. This is all working within the same financial envelope that he currently is supported with, but we are utilising it in a creative way through a personal health budget which offers him control, support and flexibility.

The support planning process has taken a considerable amount of time, and this has been critical to exploring the options in a practical sense, as well as building trust with Robert and the professional team around him. Speaking with family has been so essential too, as the family had lost all confidence within the system and so taking things slowly has enabled relationships to evolve. The building of trust has enabled the family to share the great things about Robert and his life, his personality, and his likes and dislikes, which has enabled us to support him as a whole person and not just his diagnosis. We are now understanding why his behaviours may be presenting in such a way, so we can support what **really matters** to him, rather than what is the matter with him.

There are still many things to work out but, step by step, we are working with everyone involved to look at building a good life for the longer term for Robert. However, he knows that he too needs to take some responsibility, and that the success is very much a two-way process.

"I felt like I was in prison with no-one listening to what I wanted. I couldn't understand why my family hadn't been to see me and I was so cross with everyone. CT from My Life started to visit me and, at first, I thought they were just the same as all the rest. It was when CT brought my wife to see me, I couldn't believe it after all these years. I know things won't happen overnight, but I do feel much more confident that I will get out of here." – Robert.

Case Study B:

Margaret is an 88-year-old woman. She has been living in a care home for the past two years, funded through continuing health care. Previous to this, she had lived with her husband in her own home. Unfortunately, she became too ill to remain at home and was assessed as needing 24-hour care.

Margaret suffers from 'Dumping Syndrome', which was caused following a gastrostomy for stomach cancer over 10 years ago. This has led to her developing a condition called Non-insulinoma pancreatogenous hypoglycemia (NIPH), which leads to low blood and unpredictable blood sugar levels. Margaret also has a number of other health conditions, which are managed with medication.

Margaret can become very anxious about her condition as her blood needs to be monitored closely to prevent her becoming hypoglycaemic. Margaret needs to follow a strict diet and eat at set times of the day, which someone needs to help her with. She can deteriorate quickly and become very unwell, and needs urgent medical assistance. She uses a wheeled zimmer frame to get around indoors and, when she is outdoors, she requires a wheelchair. Margaret gets out with her family but she finds it difficult getting in and out of the car. She needs to continue to be monitored and be with people who have a good understanding of her condition, how to manage it, and how to respond to her if she becomes unwell.

Margaret's husband became ill and has had a live-in carer since March. He has also been in hospital for a while, but has now returned home.

Margaret was initially comfortable in the care home; however, the family had become concerned about her when her care needs, particularly her strict dietary needs, were not being met. She was removed from the care home on a number of occasions by the family. Margaret lost weight while she was in the care home but gained weight when she was out. Margaret's family had shared their concerns with the care home, but felt that the situation didn't improve, and they were concerned for her long-term health and wellbeing. They felt that they would like to have more choice and control over the care that was provided to her, and wanted her health to stabilise and, if possible, improve.

At this point, Margaret's family were informed of our service. We worked with Margaret and her family to look at what mattered most to them and what they wanted to change about the current care. The most important thing to them was for Margaret to return to the family home with her husband.

It was challenging to write the plan, as there was an allocated budget from CHC, but this would not fund 24-hour care for her. We looked at her husband's care package and planned Margaret's to link in with this where possible. Margaret and her family were keen to have a team of PAs to support her, but were clear that having cooking skills was an essential part of the matching due to Margaret's nutritional needs. Margaret's daughter-in-law agreed to write the menus and support the PAs to embed this into the care.

We looked at the risks involved with not providing 24-hour care and considered SMART technology within the home to manage the risks. This included bed and chair sensors, which will be linked up with family members, and also monitors that they can use to check that Margaret is OK if the sensor alarm is triggered.

The plan has been developed with the family and submitted. The plan has been authorised by Lancashire and West Midlands CSU, and the recruitment has begun for a team of PAs. Focus is on finding a good match for Margaret, including similar interests and the ability to be able to prepare meals. Margaret, her husband and the family are very pleased with the outcome.

District nurses have since intervened after visiting Margaret. They are concerned that the plan will not meet Margaret's needs as she is assessed as requiring 24-hour care. This will now be discussed again with Lancashire and West Midlands CSU, as the CHC budget would need to significantly increase to be able to meet this need. It may be that another CHC assessment will need to be undertaken as Margaret's needs may have changed.

Case Study C:

Jane is a 28-year-old woman and was referred by the Integrated Neighbourhood Team. She was struggling with mobility and used a wheelchair following an operation on her spine. She has suffered from poor mental health, including PTSD relating to sexual abuse in her youth, and has tried to take her own life.

The house that Jane lived in, which had been left to her and her brother following the death of her mother, was due to be repossessed due to huge debts, and the accommodation was not meeting any of Jane's needs. It was in disrepair, there was no heating or hot water, and the electrics were dangerous and had cut out permanently. She did not have access to adequate washing facilities and could not gain access to the kitchen, so had a drinks fridge next to her bed on the ground floor.

Jane shared the house with her brother, who worked full time and could therefore only provide care to Jane for a limited amount of time each day. Due to being in so much pain, Jane has been bedbound for many years and did not have access to any community activities. She had been bidding for social housing properties for over 12 months, but had not found anything suitable.

Jane found it difficult to build trusting relationships and was very wary of accepting support from carers. She would not even consider supported accommodation if this meant that she would live where there were communal areas, due to the abuse that she has suffered in her life.

The priority for Jane was to live in a suitable property that would meet her needs, and for her to be able to live independently for the first time in her life. Support was given to ensure that she was in the correct banding for bidding for properties, and that her application was up to date. Jane was supported to view properties. A property was identified that would possibly meet her needs. A joint visit was undertaken to the property with an OT, so that they could assess the accessibility for Jane. Jane was then supported to view the property, and she felt that it would meet her needs and was pleased that it was still local to the area with which she was familiar. Joint visits

were undertaken with the Tenancy Sustainment and Housing Officers to ensure that the move would be viable, which it was agreed it would be. Support was given to apply for Housing Benefit.

Support was given to arrange to move Jane's hospital bed and to arrange a removal van on the day of the move. Discussions were had with the OT and the Social Worker to ensure that there would be essential grab rails fitted within the new property and a commode toilet for Jane to use. The OT also agreed for non-slip floors to be fitted in the property, and the Social Worker has organised for emergency carers to support the client within the home.

Jane has now moved into her own property, and the OT has fitted grab rails and provided a commode toilet. They have also agreed to put non-slip floors throughout the property, and to provide a specialist chair and ramps up to the property, so that Jane can access her garden and the community. Jane has an Independent Living Officer to support her, has had a referral to Lancashire Telecare service, and now has a falls detector in place.

She has agreed to have carers to support her within the home and is now able to have a shower once a week. Jane is now able to have her bedding changed and is offered regular, well balanced meals. Since living in the property, Jane has been able to sleep, as she feels safe and reports improvements in her mental health.

An integrated plan has been written with Jane to enable her to live independently, improve her physical and mental health, and begin to re-integrate back into the community eventually. This includes SMART equipment being installed in the property to enable Jane to be able to switch on lights, open doors/windows, control the heating, etc., and also PAs to support Jane to maintain her physio at home to strengthen her legs and back, develop her confidence and self-esteem, and assist her to access community resources. Jane is feeling much more positive about her future and is looking forward to becoming more independent.

Other outcomes achieved are:

- Jane's mental health has improved since moving into her own property and she states that she now feels safe for the first time in years.
- Reduced isolation - Jane now sees carers throughout the day, where previously she had no contact with anyone other than her brother.
- Jane feels that she has more choice and control over her life. She feels that she has been listened to and that her voice has been heard.
- Jane was living with her brother and he was providing the care for her, when he was not at work. Now that Jane has moved into her own property, her brother has also moved into his own property and is now able to live a more independent life.
- Jane would have reached a point where she would have been in crisis with her mental health and would have needed intervention.
- Jane's situation would have needed referring to the safeguarding team if she hadn't have moved out of the existing property.

Case Study D:

Barry was living with an alcohol addiction and was homeless for more than 25 years. He was well known in the local community and was identified as one of the top 100 A&E attendees at Burnley General Hospital.

He drank all day every day until he would pass out, often in the town centre or just by the roadside. In addition, Barry was also doubly incontinent and really struggled with any meaningful communication or positive decision making due to his alcohol usage. This often resulted in local services, such as police, ambulance, etc., being called in to help. He had no independent living skills and was unable to function without alcohol.

In addition, due to his lifestyle and behaviours, Barry had a hostile relationship with his family, and he has been estranged from them for a long period of time. He suffered with COPD but did not attend his appointments or manage his condition. He had also been prescribed hearing aids for his impairment, but never wore them or attended his appointments.

Barry needed ongoing support, and it was identified at the hospital that, if he was to carry on "living" the way he currently was, then he wouldn't survive another winter.

He was referred to The Calico Group, who managed to organise appropriate social housing for him with an intensive support package, and more recently a personal health budget. Barry has been referred into social care and this will hopefully develop into an integrated plan. With personalised support in place, Barry soon started to make positive changes.

The Calico Group provided an intensive support package to Barry based on teaching him new skills to support him to live independently, sustain his tenancy, and make some positive lifestyle changes, which in turn would improve his health and wellbeing.

This included providing daily visits in the morning to see him and to support him with some basic activities on a daily/weekly basis, such as getting up and dressed, support with shopping and taking to health appointments, guidance to help make positive decisions around his associates, support about his benefits and managing his money, as well as critical support with accessing locals groups, such as RAMP with Acorn Recovery Projects, and 1-to-1 sessions with drugs workers and counsellors to address his alcohol addiction.

After six months, Barry continues to do well and is leading a more positive lifestyle where he has greatly reduced his A&E attendance. He has significantly reduced his alcohol intake and has had long periods of abstinence where he has been able to communicate and make positive decisions around his lifestyle. A small but significant point is that Barry is now wearing his hearing aids, which enables him to communicate more effectively.

Critically, he has maintained his tenancy and continues to regularly access local groups and other support for his alcohol addiction, and has reconnected relationships with some of his family. By accessing these community resources, he has reduced his isolation and is now engaged in meaningful activities throughout the day.

Appendix 2a: Cost/benefit assessment

	NHS cost per unit of intervention	Prev 12m usage	Cost of usage prev 12m	Anticipated usage in 1st year on plan	Cost 1st year	Anticipated saving, based on 22 people sample	Anticipated saving if replicated across 48 people
A&E attendance	£328	50	£16,400	15	£4,920	£11,480	£25,047
Ambulance call outs	£202	45	£9,090	11	£2,222	£6,868	£14,985
hospital admissions	£3049	38	£115,862	11	£33,539	£82,323	£179,613
hospital admissions duration (2 clients)	£3049 per day	14 months (425 days)	£1,295,825	2 months (60 days)	£182,940	£1,112,885	£2,428,112
GP appts (in hrs)	£36	221	£7,956	77	£2,772	£5,184	£11,311
GR appts (out of hrs)	£70	11	£770	3	£210	£560	£1,222
MH outpatients attendance	£300	17	£5,100	6	£1,800	£3,300	£7,200
MH Inpatients appts	350 per day	30	£10,500	10	£3,500	£7,000	£15,272
MH crisis intervention	£300	7	£2,100	0	£0	£2,100	£4,581
Diabetic nurse appts	£100	16	£1,600	14	£1,400	£200	£436
			£1,465,203		£233,303	£1,231,900	£2,687,781
Cost saving						84%	

Appendix 2b: Social value assessment

Outcome measure used	Estimated amount of Improvement	Social Value of benefit to Client
Relief from health problems that limit activity	30%	£10,512
Improvement in health	30%	£85,387
Improved feeling of self-worth	33%	£1,086
Taking care of yourself	29%	£2,590
Relief from depression/anxiety	40%	£105,276
Independent living	34%	£2,504
Able to rely on family and close friends	20%	£21,375
Feel belonging to neighbourhood	48%	£29,835
Having a regular hobby	65%	£8,122
Feeling in control of life	36%	£90,052
Reduction in stress	40%	£3,584
Quality adjusted life years from moderate mental health problem	39%	£17,668
Anxiety about being a victim of crime	28%	£51,946
Total Social Value		**£429,937**

Appendix 3: Pilot partners, key skills and experience

East Lancashire CCG

East Lancashire CCG (ELCCG) have been our main commissioning partner in the project, providing support and guidance around how the local care infrastructure works, clinical oversight, and care and support plan approval. They have been a willing partner in respect of receiving information and helping us to interpret data and challenges, and have contributed to the development of a broad understanding of how personalisation can be moved forward in East Lancashire. The East Lancashire CCG will receive our final report and will assist in the dissemination of the programme locally, regionally and nationally.

- Provide a senior person to ensure good communication.
- To monitor progress and identify how lessons learned can contribute to the exceeding of NHS targets.
- Identify the correct cohort of individuals to benefit from the pilot activity.
- Support project staff to navigate the NHS system.
- Provide funding to the programme.

NHS England

NHS England is a key funding partner in the programme, providing assistance through their relationship with the East Lancashire CCG. NHS England has responsibility for the delivery of the national target around personal health budgets, and will be a key partner in respect of the wider dissemination of learning emerging from this pilot scheme. Support for this project from NHS England is driven largely through the Personalised Care Group, their liaison with the ELCCG and, more recently, with the direct involvement of the NHS's Personalised Care Group with the pilot team.

The Calico Group

The Calico Group brings a wealth of experience in the delivery of person-centred care and support to vulnerable people across East Lancashire. The Calico Group's approach to delivering services is to utilise an asset-based approach, placing the individual at the centre of the needs assessment and support planning process, ensuring that outcomes and life aspirations of the individual are prioritised alongside clinical needs. The Calico Group is particularly successful at accessing the hardest to reach individuals in society, and can demonstrate a positive track record in motivating individuals to change behaviour to deliver long-term, sustainable, positive change. The Calico Group has a long-standing relationship with its communities and, as a result, has established significant experience in working with individuals identifying with the following conditions:

- Complex needs
- Mental health and learning difficulties
- Substance misuse
- Debt and finance-related issues
- Domestic abuse
- Housing and accommodation
- Social care
- Social isolation
- Family intervention and relationship breakdown.

Alocura

Alocura has an in-depth knowledge of community-based health and social care markets and how to shape them. The company has developed their experience in personal budgets, including the use of innovative systems and strategic procurement expertise. This includes the often complex administrative process aligned with marketplace management and shaping. Alocura was established to bring these skills to the health and social care markets, including the following key input to the pilot:

- Pilot programme management; strategic development support
- Provision of software and 'transparent transactions'
- Brokerage administration and support
- Programme facilitation and MIS data
- Market analysis and shaping – support for procurement.

My Life

My Life was established in July 2012 as a charity in direct response to the demand for third sector partners to be involved in personalisation. The organisation is led by Caroline Tomlinson, who pioneered the approach to delivery of personal budgets, and was amongst the early adopters achieving one of the first social care budgets in England. Caroline co-founded the innovative organisation 'In-control' that raised the profile of personalisation to a national platform.

My Life exists to support families, often in significant trauma, to do something fundamentally different with their health and lifestyle choices. They sit in the space between the individual and health service commissioner, working through the problems faced by the individuals and translating this into an effective care plan that makes a real difference. My Life's real value is found in the high end complex cases that require new thinking and innovative solutions. My Life brings forward all the experience they have developed since 2012, contributing the following to the pilot:

- Intensive training for The Calico Group staff around personalisation and care planning
- Support on the development of systems and paperwork
- Experience/best practice – solution focus
- Lead on complex cases
- 'Routes to Employment' course for personal assistants.

Lancashire County Council

Lancashire County Council is the statutory body for funding of the adult social care budget. In the initial pilot areas, Lancashire County Council staff have provided expertise around some of the complexities of funding for adult social care, particularly in the cases where joint funding has been required from both social care and health-related pots.

Appendix 4: Governance, leadership and management arrangements

To achieve the outcomes required of the pilot scheme, we established a partnership steering group.

This group had representation at a senior level from the following organisations:

- East Lancashire CCG
- Burnley Health and Wellbeing Panel
- Lancashire and West Midland CSU
- Lancashire County Council
- The Calico Group
- Alocura
- My Life
- GPs.

The steering group had a monthly schedule of meetings where progress towards the achievement of objectives, barriers to progress, key lessons learned, and any additional resourcing or support needs, were discussed. In addition to the steering group arrangements, an operational team was in place to drive forward progress around key areas. The following roles and responsibilities were established for key partners:

- Calico Enterprise – Person-centred support, advocacy and care planning in advance of marketplace engagement for mid-level complex needs and mainstream referrals for personal health budgets. Management of broader partnerships as outlined below.
- My Life – Care planning for high level complex needs in advance of marketplace engagement and consultancy support to The Calico Group around skills development in care planning approach.
- Alocura – Provision of software to enable marketplace engagement and service categorisation. Development of products where required to establish a functioning market place.