

A Report for the Money Advice Service

What Works Fund

Financial capability of patients attending NHS units
for Renal Services and Inherited Metabolic Disorders



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Date:
April 2018

Funded by



Acknowledgements:

Special thanks to all healthcare staff and the patients who kindly took part in the research required for this report, and freely gave their time and support to enable the evaluation to be completed.

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Executive Summary

Context

Between January 2017 and March 2018 Auriga Services was funded by the Money Advice Service (MAS) under the *What Works* Fund to develop the financial capability of patients with renal failure and people with inherited metabolic disorders (IMD). The project was delivered through face-to-face advice and support in healthcare settings in Birmingham and the West Midlands. The project worked with 409 renal and 73 IMD patients between January 2017 and January 2018.

Project interventions initially focussed on delivering welfare advice and benefits maximisation to patients on a one to one basis. The funding from the What Works Fund enabled the service to be expanded into the provision of information and guidance to help patients understand and extend their financial capability. To support the advice work, a set of fact sheets were produced and distributed to help participants understand financial capability concepts and to give practical advice on managing budgets, utility tariffs, online banking and other financial products and processes.

Evaluation approach

The main research question posed was: To what extent do interventions in a healthcare setting improve patient engagement with financial capability? To answer this, the project reviewed the outcomes of welfare benefit interventions and financial capability amongst participants. The relationship between the interventions and change in physical and mental wellbeing was then reviewed.

The evaluation included a baseline and follow up survey, for which there were 152 baseline and 78 surveys returned respectively. A control group who received no direct intervention was included in the evaluation. A set of 28 qualitative interviews and observations with medical staff, patients and project staff were also commissioned to review project process and outcomes. Eight patient case studies were produced.

Key findings

Interventions delivered by the project to those outside the control group supported patients to maximise their income from welfare benefits, economising on bills and minimising expenditure, gaining access to the most economical tariffs, accessing in-kind benefits, and where appropriate, rescheduling payment plans.

The timescale for the project was truncated due to a variety of factors. This included a change in the delivery method of the additional financial capability activity, from workshops to more tailored one to one advice. This impacted on the numbers of survey returns and, to some extent, the project methodology.

Interventions with IMD patients needed extra time to establish than those with renal units, due to Auriga already having a presence within renal units, and because of the different demographic of patients and logistics of clinic based delivery.

The project processes worked effectively, with very high levels of confidence shown in the project team by patients and by health staff. Patients and clinical staff reported the ease and efficiency of the referral and intervention process.

Patients were able to draw on an advice service within a trusted and familiar environment. Healthcare staff emphasised the importance of having a service coterminous with other health interventions. Welfare advice and financial capability support delivered together is considered a strong working model, based on interviews with healthcare staff and patients.

Diagnosis and treatment for renal failure had in the majority of cases led to patient's livelihoods being lost. This seriously disrupted their family life and relationships, causing negative financial and emotional impacts on patients. Patients were also facing challenges around the definition of disability related to the changes within the welfare benefit system. Few patients had any financial buffer against the impact of being diagnosed with renal failure, or their savings had run out.

The project team realised substantial additional income to individual patients totalling c. £581,000 from sources including welfare benefits, grants and savings on utility tariffs. This increased their household budget and reduced the stress on individual patients and their families. Patients reported that they were able to budget more effectively as a result, and 'getting by' when they had previously been unable to cope or struggling. A number of patients reported being able to return to their former methods of setting clear weekly or monthly household budgets, including setting aside savings in some cases, after their household income had been restabilised, as well as managing repayments for arrears more effectively.

Patients described a variety of positive changes that came about with their increased income including: being able to make improvements to their diet making it more suitable for their health condition; heat their houses without worry; and keep themselves and their houses cleaner with less concern about water bills. Other improvements for individuals were: increased feelings of independence through the ability to continue to drive and park using a Blue Badge; being safer and more independent in their own homes with additional aids and adaptations to enhance their mobility; and an ability to feel secure in their tenancies or with their mortgages where appropriate repayment plans were arranged.

The survey indicated a slight improvement in the attitudes and confidence of a small number of patients outside the control group towards financial capability matters, including shopping around for the best deals. The proportion able to use the internet to access services remained very low, however. Questions regarding planning ahead, feeling in control and buying things to cope with their health condition showed higher scores by survey 2. The survey indicated that for welfare benefits and financial advice respondents would still prefer to see a specialist advice worker, although their confidence to claim benefits increased, as did their confidence to speak with friends and family about their finances. No changes in attitude were evidenced amongst the survey responses for the control group.

A majority of patients interviewed recalled discussions with the project team around financial capability matters, especially regarding utilities and tariffs. Interviewees indicated that they preferred to receive support from a trusted adviser, on a one-to-one basis, and that this was more

effective than the provision of written information via the fact sheets. Information being delivered appropriately by a knowledgeable project worker, adapted to the knowledge level and situation of the individual patient, therefore appeared to be both preferred and more effective.

The financial capability of patients was strongly linked to their previous experience of managing their household budget. Where their income was increased they had more confidence and capability, as well as the resources to make financial decisions and plans. Where patients had previously had strong financial capability, with support from the project team, changes in confidence and financial decision making were strongest.

Conversely, patients who suffered an income shock, and additionally had no experience of household budgeting, were at a very high risk of falling into financial crisis and were vulnerable to abuse. These patients reported their financial situations being stabilised through the project, reductions in stress and an overall increase in confidence about the future. However, change was not yet apparent in this group regarding their ability and confidence to manage their financial affairs independently, usually inhibited by low digital confidence or ability. A number of factors would have to interplay to determine whether they had the capacity to change over a longer period and would also be dependent on health, family and management of post diagnosis psychological crisis. Longer-term follow-up would be required to check if behaviour change could be consolidated.

Methodological limitations

These two patient groups are particularly hard to research due to their health and the mental health issues arising from their conditions. Additionally, their complex medical schedules of appointments and treatment adds logistical complications to the research. The project participants frequently experienced health and financial crises which made consistent and reliable data hard to collect. Qualitative interviews with patients and health staff have proven the most effective means of evaluation, and patients generally responded well to one to one discussion.

The patient survey, especially the baseline survey, provided a valuable indicator of the views, attitudes and behaviour of renal patients, but did have a number of limitations. These relate to:

- The large size of the population group (people with IMD and renal patients) versus sample size
- The fact that this was an opt in survey
- Use of a Likert scale reducing scalability of samples
- The high level of attrition between baseline and follow up
- The control group being within the main survey and delivery site.

Qualitative interviews have given a good level of information and opinions which indicate potential transferability to other healthcare contexts, especially other renal dialysis centres, but also other patient groups with chronic debilitating illnesses. Causality of change is difficult to establish, but alongside supportive family and positive health care interventions, the project has provided an indicator of the benefit of financial capability work in healthcare settings. Patients had typically not sought support from elsewhere before contact with Auriga indicating that these patients may well have fallen through the net without the project. The project also provides valuable insight into these

under researched groups. Learning and sharing of the insights gained has taken place throughout the project, through training, conferences and social media.

1. Overview of the project

At the beginning of 2017 Auriga Services received funding from the Money Advice Service (MAS) under the *What Works* Fund to deliver a project that aimed to develop the financial capability of patients in specific health care settings. These included people with renal failure under the care of the University Hospital Birmingham (UHB), and people with Inherited Metabolic Disorders (IMD) also under the care of the UHB. The project ran until the end of March 2018.

The project aimed to identify the most effective ways to test and improve the financial capability of both patient groups through a variety of interventions. These included:

- welfare benefit advice and income maximisation
- face to face advice and support to patients on their household income and budgeting
- drop in money management information sessions
- provision of fact sheets on financial capability, energy suppliers and various other topics
- one to one information sessions on financial capability.

These were delivered in the healthcare setting or at home as appropriate for each patient.

The renal patients provided the largest pool of the two patient types, and have constituted by far the largest intervention group within the project.

Auriga services

Auriga operate as a not-for-profit organisation. They deliver a range of management services for clients that include charitable trusts, utility companies, benevolent funds, local authorities and the NHS. These services include grant giving to individuals and community organisations along with management of vulnerable customer support schemes. Auriga have their own Ofgem approved online energy tariff switching service, and offer debt and welfare advice that includes representation at appeals and tribunals.

The project complemented Auriga's existing advice and support work with haemodialysis (renal) patients, which have been delivered under contract for UHB since May 2016. This service was instituted by the hospital trust due to the high level of need amongst patients for welfare benefit advice and support, to tribunal level. The work with IMD patients was new to Auriga but was also delivered under a contract with the hospital trust. This contract aims to use the same delivery model of financial advice and support for people in a healthcare setting, and was building on their experience of delivery in a healthcare context.

At the outset of the project, Scott Morrison from the Money Advice Service commented, in a video commissioned for the project that: *"The Auriga bid was completely unique amongst all the 58 projects in the What Works Fund. There is a distinct lack of evidence on financial capability work with people within long term illness within a healthcare setting."*

Patient group and their characteristics

The patient groups targeted by the project are quite distinct demographically, as well as having a very different relationship to the healthcare units where they receive treatment. This made for a

potentially very interesting set of comparisons around the health gain of advice and support to build financial capability across the two groups.

It is helpful at this point to detail some background on the two patient groups, as this has significant implications for how the work was planned, as well as the implementation process and outcomes.

Renal patients

One in eight of the population will develop Chronic Kidney Disease (CKD) within their lifetime. CKD can exist on its own or in combination with other long term illnesses. The disease is incurable and affects kidney function which increases the risk of renal failure. Approximately 50 % of all people over the age of 75 will have CKD and it is more common within Asian and African communities where it occurs earlier in life.

Alongside population ageing, causal factors for CKD include obesity and type 2 diabetes. As these conditions increase in the population, so too is the incidence of CKD¹. For example, an estimated 40% of people with both type 1 and type 2 diabetes will develop CKD during their lifetime². The proportion of adults in the most deprived Index of Multiple Deprivation (IMD) quintile reporting that they had never been told they were at risk of kidney disease is double the proportion in the least deprived IMD quintile (8% and 4% respectively).³ Hence there is a strong relationship between CKD and socioeconomic deprivation levels.

Renal failure can also result from the use of certain drugs, or as a result of surgery, from inherited conditions, and from elevated blood pressure including preeclampsia in pregnancy. The majority of patients have other concurrent illnesses and long-term conditions, which were either the cause of the renal failure or are a consequence of renal failure. However, kidney failure is often called the 'silent killer' because of the lack of symptoms until the disease is quite well advanced. Kidney disease is often detected by routine testing in people with diabetes or hypertension.

Kidney failure is a life-shortening condition. A person with stage 5 kidney disease has end stage renal disease (ESRD) and dialysis or a kidney transplant is needed to extend their life. Most people requiring haemodialysis require treatment around 3 times a week for 4 hours with an additional 4-8 hours of recovery time. The median age of renal patients at haemodialysis units is 65 making the majority either of non-working age or close to retirement. However, there are also younger people with renal failure resulting from genetic disorders, disease or kidney damage who are on dialysis.

Home haemodialysis allows more flexibility (for example having a session for 2 hours every day at a time of the patients choosing). Someone is required to be on hand throughout the home dialysis process.

Kidney failure and its treatment affects not just the patient's health but their ability to function within society and their relationships with family and friends. Renal failure can make the patient weak, fatigued and often depressed. Up to one third of haemodialysis patients have depressive

¹ *Health Survey for England 2016: Kidney and liver disease*, December 2017, NHS Digital

² *Preventing kidney failure in people with diabetes, Position Statement, August 2016, Diabetes UK*

³ *Health Survey for England 2016: Kidney and liver disease*, December 2017, NHS Digital

symptoms consistent with the diagnosis of depression. Depression among patients with chronic kidney disease has been associated with earlier initiation of dialysis, and for those already on dialysis has been associated with higher rates of hospitalization and death.⁴ Patients can also experience difficulties with mobility and concentration. All of these factors significantly impact upon the confidence of patients and their ability to self direct their finances, or access appropriate financial support.

UHB Trust has the second largest renal programme in the UK. Numbers change as new patients come into the service, and as this is a very severe life-limiting condition, a number die each year. The renal units are located across the UHB catchment area which encompasses rural areas such as Herford and Worcester that have pockets of deprivation mixed with much less deprived areas, through to urban inner city areas across Birmingham and Sandwell where there are high concentrations of deprivation. According to the Indices of Deprivation 2015, Birmingham is ranked as the 6th most deprived Local Authority area in England and Sandwell is ranked as the 13th most deprived Local Authority area.

Inherited Metabolic Disorder patients

Inherited metabolic diseases (IMDs) are a group of over 750 conditions caused by deficient activity in a single enzyme. The conditions include:

- biochemical defects in carbohydrate metabolism
- disorders of amino acid and fat metabolism
- lysosomal storage disorders
- mitochondrial diseases
- organic acidemias
- urea cycle disorders
- fatty acid oxidation disorders
- disorders of lipid metabolism.

Each IMD has a separate set of causes and manifestations. Inherited metabolic disorders vary from acute life-threatening disease to less life threatening degenerative disorders. The demographic of IMD patients is broad, with a large percentage being of working age, with the largest concentration of patients in their 20's. This is also a diverse population with a multi-ethnic background of whom approximately one quarter have diagnosed learning disabilities.

Patients attend the IMD clinic around once a year for consultant appointments and check-ups. They often attend with carers, given the high level of learning disability and their general ill health. Younger people often attend with their parents.

The IMD clinic is based in the Centre for Rare Diseases in Birmingham. The IMD service at UHB provides care for over 500 patients with an IMD diagnosis. All of these patients are seen in an outpatient facility.

⁴ *Chronic Kidney Disease: Depression in Chronic Kidney Disease*, Renal and Urology News, 2018, Haymarket Media

Ill Health and financial capability

Financial capability has been defined as the ability to manage their money effectively and make good financial decisions given their particular circumstances. The Money Advice Service have developed a suite of financial capability outcome frameworks that focus on the following internal and external components:

- Ability (knowledge and skills)
- Mindset (attitudes and motivations)
- Connection to financial products, services and tools.⁵

The Auriga project was premised on the fact that renal and IMD patients cannot easily improve their own financial capability due to a range of barriers limiting all three of these components. Numerous studies have pointed to the financial difficulties that result from periods of illness or longer term disability. Indeed, The World Bank reports that in an analysis of case studies of people and households that have become poorer worldwide, the most common reason was illness, injury, or death.⁶ References to further analysis studies form part of the next section.

Changes that arise due to ill health can impact beyond the immediate and obvious consequences. They include:

- the overall change in general physical and mental well-being
- changes within the family role (e.g. partner becomes a carer, loss of household income)
- employment status changes (unemployment due to incapacity, loss of household income)
- accommodation (adjustments may be needed to the accommodation, potential arrears due to loss of income)
- education (accessibility issues due to reduced opportunities, incapacity or disability)⁷
- finances (lack of savings buffer, can't keep up with commitments, increased expenditure due to travel and hospital parking).⁸

People with long-term conditions including people with renal disease and people with IMD can qualify for a whole range of benefits, tax credits, grants, payments and concessions. These include help with:

- transport costs and parking
- help to buy support from a carer
- housing benefit and council tax reduction
- Income Support
- Working Tax Credit
- VAT exemption
- non means-tested benefits to support disabled people – Disability Living Allowance (DLA) or Personal Income Payments (PIP) - which is gradually replacing it.

⁵ Bagwell,S., Hestbaek,C., Harries,E., Kail,A. (2014) Financial capability outcome framework. New Philanthropy Capital

⁶ Mukherjee, K., Poverty as a cause and consequence of ill health, Article 26, [Volume 2, Issue 4 - Serial Number 5](#), (Autumn 2015), Page 209

⁷ Grant, U., Health and Poverty Linkages: Perspectives of the chronically poor, Background Paper for the Chronic Poverty Report 2008-09 (February 2005) Chronic Poverty Research Centre

⁸ A recent study indicates a number of these issues for households in Protecting Our Families, (March 2017), Aviva

Healthcare staff within the IMD unit had a number of specific concerns regarding their patients and their ability to access their welfare benefits, and in gaining the right levels of PIP relating to the severity of their condition. This group also has more issues than renal patients with Job Seekers Allowance, as the patients tend to be younger and are more likely to be assessed as fit for work, which commonly becomes the cause of an appeal or tribunal. The type of benefit issues they wanted Auriga to support patients with through the contract included:

- patients not claiming the right benefits, and not aware of their entitlements
- patients claiming Job Seekers Allowance being unable to fulfil a minimum amount of time searching for jobs weekly, and receiving benefit sanctions
- patients who receive DLA expected to partake in courses and refusal to do so resulting in sanctions, including DLA being withdrawn for 12 months
- patients applying for hardship payments (30% of DLA) which then has to be paid back leading to financial difficulties
- transition from minor to adult and moving onto PIP with different tests than DLA which they have previously received
- patient benefit appeal and tribunal cases
- arrears arising through these issues.

Auriga is familiar with delivering support to patients who need advice with welfare benefits, arrears or other urgent interventions. The funding from MAS enabled Auriga to widen the scope of their current activities to encourage further the financial capability of patients, supporting MAS objectives to enhance people's skills and knowledge around money management, access financial products and services and avoid unmanageable debt. The methods introduced aimed to increase knowledge and skills, mindset and behaviour, and also provide a greater connection to financial products, services and tools.

The project posited that welfare advice would be welcome, especially in the light of changes within the benefit system, especially the move from DLA to PIP that would affect the majority of renal and IMD patients, but also that the project could be effectively delivered directly in healthcare settings. Healthcare teams were to play a central part in guiding patients towards advice from the project team, requiring NHS approval of the project methodology. The fact that Auriga already had established contracts within the healthcare environment increased the likelihood of successful referral into the project by healthcare teams.

Research questions

The key research questions for the project were developed in relation to the *What Works* Fund question that asked: *How can we help working age adults to improve their financial capability, develop budgeting and tracking habits, build up a savings buffer to withstand financial shocks and/or set financial goals for key life events?*

The main research question the project posed was: *To what extent do interventions in a healthcare setting improve patient engagement with financial capability?*

Specifically:

1. Are interventions in the healthcare setting improving patients understanding and knowledge of financial matters and helping them manage their money better?
2. Is an immediate focus on welfare benefits and income an effective way of leveraging wider engagement in financial capability topics (e.g. budgeting and planning ahead, making better financial decisions)?
3. Does improving a patient's ability to manage money (knowledge, skills and attitudes) affect their wider physical and mental wellbeing?

The *What Works* Fund is particularly interested in the sections of the population classified as 'struggling' - that is, people with significant financial commitments but relatively little provision for coping with income shocks, and 'squeezed' - that is, people who struggle to keep up with bills and payments and to build any form of savings buffer, the least financially resilient and the most likely to be over-indebted.⁹ The socio-economic demographics of the target patient groups for the project, noted above, means patients are most likely to be drawn from the 'squeezed' section of the population, but will also be within the 'struggling' section, as a result of their illness affecting household income negatively. Additionally, a smaller proportion of patients represent 'cushioned' individuals because they are part of an affluent household group. So the project offered the opportunity to carry our research and interventions with a cross section of age groups and across MAS defined macro-segments within the overall patient population.

There is little literature on financial capability interventions in the healthcare setting, particularly with specific patient groups and specific conditions. However, there is literature on the positive impact of welfare advice in healthcare settings. This suggests that there have been positive impacts on recipients' disposable income, but that beneficiaries of welfare advice also reported feeling more valued and included. Various studies have noted that beneficiaries whose income had been increased felt greater levels of independence, dignity, participation and identity, and is why contracts to deliver welfare benefit advice are contracted by health trusts for certain patient groups.¹⁰

Evidence from a number of welfare/financial advice studies in a healthcare context has noted a significant improvement in measures such as vitality, role functioning, mental health, general health, tolerance of pain and emotions. One study showed that increased income from welfare rights advice was associated with a reduction in physical pain and mental health-related issues such as anxiety and a slight reduction in GP consultations.¹¹ This points towards the 'advice plus financial capability' model having considerable beneficial outcomes for patients.

There is also a strong rationale to add financial capability work to welfare advice services. Financial wellbeing is most strongly correlated with factors such as income, household composition, housing tenure or work status. Welfare benefit work can affect these directly through increasing income.¹²

⁹ Market Segmentation: An overview (March 2016) MAS

¹⁰ *Just what the doctor ordered: Welfare benefits advice and healthcare*, A report by Neil Bateman for Age Concern England 2008 summarises much of this research.

¹¹ Adams, J., White, M., Moffatt, S., Howel, D., Mackintosh, J. (2006) *A systematic review of the health, social and financial effects of welfare rights advice delivered in healthcare settings*. www.biomedcentral.com

¹² *Measuring financial capability – identifying the building blocks Understanding what drives or inhibits consumers' financial wellbeing and resilience An in-depth analysis of the UK Financial Capability Survey* (November 2016)

Low financial capability has been shown to have significant and substantial psychological costs over and above those associated with the low income itself. Recent research has also revealed how conditions of scarcity - being short on money, time, or other resources - can directly influence both reasoning and behaviour. Notably, this work has found that scarcity often reduces mental 'bandwidth', increases stress, constrains attention, and hurts decision making.¹³ Conversely high financial capability is associated with higher levels of psychological health for both men and women.¹⁴

Improving people's financial wellbeing requires a move from the experience of scarcity (those unable to keep up or constantly struggling) to increase bandwidth, thus making them more receptive to interventions at the level of behaviours, enablers and inhibitors to be successful in improving financial wellbeing.¹⁵

Compared with the working-age population, confidence managing money and skills, plus knowledge, are unusually low for both benefits recipients and unemployed people.¹⁶ Given the high levels of patients with IMD and renal failure that are receiving benefits, the cohorts chosen for this project were ideal. Changes within the welfare benefit system, particularly the introduction of PIP and ESA, have in some cases had a negative impact on patients, making the interventions provided by this project more are even more relevant.

By making interventions at the level of income, there was potentially a greater chance of successfully changing the financial wellbeing of patients through behavioural nudges, removing inhibitors and developing enablers.

Additionally, the project was building on the Working Age Strategy objective: *To maximise their impact and reach, more needs to be done to embed financial capability interventions in services that people already look to for support during major life events.*¹⁷ The context of delivery of the project, within trusted health sector providers, fulfils this suggestion regarding point of delivery for financial capability interventions.

¹³ Shah, A. K., Mullainathan, S. & Shafir, E. (2012) *Some consequences of having too little*. Science, 338, 682-685.

¹⁴ Taylor, M., Jenkins, S., Sacker, A. (2011) *Financial capability, income and psychological wellbeing*. ISER Working Paper Series 2011-18

¹⁵ *Financial Capability and Wellbeing*, A qualitative report by TNS BMRB (March 2015)

¹⁶ *Financial Capability in the UK 2015, Initial results from the 2015 UK Financial Capability Survey*. (2015) Money Advice Service.

¹⁷ *Financial Capability Strategy for the UK, Working-Age People* Priority 6

2. Overview of the evaluation approach

The evaluation set out to answer the key research question: To what extent do interventions in a healthcare setting improve patient engagement with financial capability?

The sub questions to this included:

- Are interventions in the healthcare setting improving patients understanding and knowledge of financial matters and helping them manage their money better?
- Is an immediate focus on welfare benefits and income an effective way of leveraging wider engagement in financial capability topics (e.g. budgeting and planning ahead, making better financial decisions)?
- Does improving a patient's ability to manage money (knowledge, skills and attitudes) affect their wider physical and mental wellbeing?

The project has developed a Theory of Change plan to support its activities, and this helpfully details the expected outputs, outcomes and impact of the intervention. The Theory of Change is attached at Annex 2.

The outcomes the evaluation aimed to measure included:

The patient is:

- able to understand benefits entitlement
- accessing a wide range of benefits and grants
- accessing and using financial products and services, such as bank accounts and money advice.

The patient has:

- maximised their welfare allowances
- less debt
- a positive attitude, is motivated and has goals in relation to money
- increased general wellbeing.

In addition, it was thought helpful to assess:

- NHS services saved as a result of patients improved wellbeing.
- That unit/clinical staff are aware how to identify needs and make effective referrals.
- Whether Auriga has improved and shared knowledge about the financial pressures and needs of patients with long-term health conditions.

Impacts to be assessed were:

- whether patients suffering from long term illness have improved their financial capability as a result of more in-depth support
- if there is a reduced likelihood of patients suffering from anxiety and depression as a result of intervention
- whether patients suffering from long term illness have improved psychological wellbeing
- if patients have been given confidence to use their skills through the project
- cost savings to the NHS

- whether patients have a more positive mindset and outlook after intervention.

In order to answer these questions, and assess any measurable outcomes and impact of the projects, a baseline and follow up survey were devised, including a control group against which change would be measured. This was administered by project staff. A set of externally delivered qualitative interviews was also put in place in autumn 2017 for patients, clinical staff and project staff. The qualitative interviews assessed process and outcomes, and developed 8 case studies (see Annex 8 for these full case studies).

Survey process

A baseline and follow up questionnaire was devised by Auriga in quarter 1 and responses were collected by them throughout the project timespan, through to the 8th Feb 2018. The survey used a Likert scale which scored answers as below:

- Strongly disagree: Score 0
- Disagree Score 1
- Agreed Score 2
- Strongly Agree Score 3

The survey was administered twice, first as a baseline and then repeated as a follow up survey, with each patient that consented to take part on both occasions. The total number of baseline surveys administered was 152. Of these, 78 also returned the follow up surveys including the control group, whilst 74 patients dropped out or were unable to return the stage 2 survey. This is an attrition rate of 48%.

A control group of 41 who had no intervention around financial capability or welfare advice of any kind from Auriga, was included in the research methodology. Of these, 22 completed both a baseline survey, and a follow up survey, with an attrition rate of 42% (16 patients).

The attrition rates were related to the following factors recorded against each non return in order of likelihood below (numbers for each can be found in annex 6):

- patients lacking the capacity to participate further through lack of a translator or a disability and no ability to administer the follow up in these circumstances
- patients no longer wishing to participate further in the study
- the patient not being reapproached due to being in very poor health
- patients who initially completed the survey dying before return of the second survey
- appointment times at unit being inconsistent, and the survey administrator being unable to catch up with the patient.
- patients not attending clinics regularly enough to collect the follow up survey
- patients receiving a transplant, and no longer being at the unit
- patients moving home or being out of the country for a long term
- the survey being posted to the patient, and not being returned

The IMD patient group had a particularly low level of participation in the survey for reasons explained in more detail in section 4.

The survey sample

The survey was optional at both stages and only offered to patients willing and able to take part and, therefore, was not a random sample. Hence, the participants were more likely to be motivated to participate than those who did not. Some patients did not speak English, and interpreters had to be found (usually family members). The relative illness and depression of certain patients also excluded them from taking part in aspects of the project, especially the financial capability survey and follow up intervention.

Additionally, Auriga is well established within the renal dialysis units, and their publicity materials are around all of the buildings. A relatively high proportion of the patients who participated in the survey would have received an intervention from Auriga at some point during their time on dialysis and may have known the individual administering the survey. However, the control group did not receive an intervention from Auriga except the survey administration itself.

To mitigate against any potential biases regarding prior knowledge of Auriga within the control group, the survey asked questions regarding the patient's financial capability, not for their views on Auriga. Views on Auriga and the project process and outcomes were covered instead in the qualitative interviews carried out by an independent evaluator. More details on the methodology can be found in section 5.

Qualitative interviews

Qualitative interviews with patients took place between late December and through to early February. Interviewees were brought into the study through the following criteria:

1. They had received an intervention by Auriga staff – either welfare support or the financial capability fact sheets and discussion or both.
2. They were capable of being interviewed (were well enough), had relevant information to impart, and practical details such as their time and day of dialysis, and whether they would need an interpreter.
3. The patient signed a consent form to agree to take part in the evaluation.

Given the complications of shift patterns for dialysis patients, and the need to gain consent for interview, this method of recruitment to the evaluation cohort was considered the only practical and cost effective way of determining the interview sample.

The use of welfare staff to gain consent forms worked well, as they had the trust of their clients, and were able to explain what the research was for, and why it would be helpful to take part. Therefore patients were happy to participate and refusals were not experienced. The piecemeal nature of gaining consent, the potential for patients becoming too sick to participate or their passing away, and the requirement for a very quick turnaround time from project intervention to interview, plus issues of lack of concentration and memory problems amongst patients were central to the choice method of recruitment.

There was a possibility of bias within this methodology, in that welfare staff may select patients who had a positive view of the intervention they had received, but this was a risk that was, on balance, one that had to be accepted given the many limitations (see below) on the research already impinging on the interview process and schedule.

Sixteen patients consented to take part in the interviews. One was carried out by phone as the patient was based in rural Herefordshire. The others all took place face to face. One took place in the home of the interviewee, whilst the others took place at the bedside of the patient undergoing dialysis. All patients consented to be recorded during the interview.

Again, IMD patients were not able to take part in the interviews for reasons given in sections 4 and 7. However, the IMD unit staff and project worker were interviewed and one observation within the clinic took place.

Interview limitations

A further factor in the interview process was the relative state of health and mind at the time of the interview. The nature of dialysis is such that patients become very fatigued through the hours they spend on the dialysis machine, and they could be too tired to be interviewed at the allotted time of interview or to manage a full research interview. In one case an interview was cut short on this basis.

The memory loss and sometimes confusion of patients including those who had had strokes or other memory affecting disorders meant lengthy interviews were not possible or productive in many cases. The complex and multi-faceted nature of welfare interventions – touching on welfare benefits rules, household budgeting, grant terms and conditions etc. made recall of the specific interventions by Auriga difficult for patients. It was difficult for some interviewees to recall key dates, or the names of specific benefits they received.

The mental distress of patients in a post diagnosis crisis, and the associated shock and resulting life changes being often coupled with a financial crisis meant complex interview questioning was unproductive and potentially distressing to some patients. Questioning regarding debt situations, financial abuse, family break up and loss of employment in these cases were too distressing for any in-depth depth probing.

The multi-faceted nature of the patients' medical conditions (e.g. diabetes, physical disability, heart conditions) and associated medical interventions, meant that identification of specific health changes associated with an improved household income, less debt and ability to manage financial affairs was not possible.

Initially the lack of confidentiality of bedside interviews was considered a potentially inhibiting factor. However, a review of the first 3 interviews was undertaken to enable any adjustments of the topic guide or the interview process to take place, and it was clear that the nature of the renal units, where there is a constant noise and activity, actually afforded privacy to the patients. Staff come to check patient's progress, reset alarms on machines, administer medications, and bring refreshments. Patients watch TV, listen through headphones and/or sleep for much of their dialysis session. In all cases the patient beside the interviewee was asleep, with medical staff, or listening through headphones.

Therefore, the rest of the interviews took place at the bedside, but where the unit was quieter, the interviewer and interviewee sat close together, and in some cases medical staff moved away to afford more privacy.

Given these limitations and restrictions on interviews noted above, the interviews were largely restricted to 30-40 minutes. It was important not to fatigue the patients further, or ask questions that may prove too distressing or intrusive. One interview was cut short as the patient was clearly in mental distress. One interview was cut short as the patient was too fatigued. Having said this, some patients were bored and keen to talk, and chatted about the topics within the topic guide quite openly.

Interview process

The age range of the interviewees was from 39 to 79. There were interviewees from white UK backgrounds (6 patients), African Caribbean (4) and Asian (6). Eight were male and 8 female. The observation with an IMD patient was white UK, female, age unknown. The amount of time they had spent on dialysis varied from 22 years as the longest, through to a woman who was just about to start dialysis for the first time.

The interviewees were very mixed socially. Several were homeowners with mortgages, others lived in social housing or private rented accommodation. The majority had previously had blue-collar occupations, and would be classified as C and D social group, having been manual or clerical grade staff. However, one interviewee was white collar as a loss adjuster, and another had been a teacher and school counsellor when in Zimbabwe, but had come to the UK to help her daughter raise her children – and had not worked in paid employment in the UK. Only one was working at the time of the interviews, and the others were either full time carers, and/or were living on their welfare benefits, a state pension or from the earnings of a working partner.

3. Key findings: outcome/impact evaluation

The outcomes and impact were assessed through the three main research methodologies. The majority of the evidence for the evaluation has been drawn from the qualitative interviews with renal patients. In addition, Management Information data has been examined to assess key outputs. The commentary below covers output data, the findings from interviews, and then reports on the survey. More details on the survey can be found in Annexes 6 and 7.

Uplift in welfare benefits and other income

The Auriga project supported patients to maximise their household income through:

- accessing additional welfare benefits
- accessing grants
- supporting applications for Blue Badge and Disabled Persons Bus Pass
- accessing special transport schemes for renal patients
- supporting patients to get local authority /housing providers to install home aids and adaptations
- accessing schemes to reduce council tax for disabled people and carers
- accessing utility provider special schemes that provide lower tariffs or discounts
- supporting applications for medical exemption cards / free prescriptions

In addition, they increased financial wellbeing in a number of other ways including stabilising housing situations for patients including making more suitable repayments for arrears on tenancies, and in some cases supporting patients in finding more appropriate accommodation. Patients were also placed on the Priority Service Registers (PSR) of relevant utility providers that would ensure that in the event of power outage or water interruption they would receive priority interventions.

The additional income and direct value of items gained for patients are both actual and some not yet realised at the time of publication. The details are below:

Renal patients

- Financial gains identified for patients totalled £772,676
- £580,968 of the above gains identified have been realised for patients and this value will increase as further outcomes are achieved

Other help provided included making referrals to:

- Occupational therapy services
- Appropriate housing support
- Social services or other relevant support agencies

IMD

- Financial gains identified during the project term totalled £121,221
- £30,420 of the above gains identified have been realised for patients and this value will increase as further outcomes are achieved

Financial consequences of diagnosis

The financial situation of interviewees had in the majority of cases changed drastically when they were diagnosed. Typically renal patient interviewees had worked prior to their diagnosis, but most of the interviewees had then fallen ill and taken sickness time from work, resulting in their dismissal or resignation from their job. A number of the women interviewed had not previously been in paid employment, and been full time carers prior to diagnosis.

The interviewees outlined other major changes that had taken place within their family and relationships as a result of becoming ill and entering into the dialysis programme. None reported having any insurance against long term illness, and the majority fell back onto state benefits for their income, although others relied on using life savings, selling their property or relying on a working partner.

In a number of cases a relative of the interviewee, their partner or in one case a sister, had taken on the full time care role for the patient following their diagnosis and starting regular dialysis. Again this had major implications for their family's financial position whereby the carer gave up full time work and instead claimed carer related benefits. Therefore, two incomes were lost to the household. In several cases this led to the fear of or actually becoming dependent on adult children living with the family to pay mortgage payments or rent. It also left carer and the cared for vulnerable to benefit changes. As one interviewee reported, both her own and her husband, as her primary carer, found themselves simultaneously having their benefits stopped, and having to go to Tribunal to regain them.

Two interviewees directly attributed their relationship break up to the renal failure. One described how her daughter had requested she leave their home once it became clear she could no longer be a help to her daughter with her children, and that she did not wish to be her mother's carer. One sold the family home after his wife said she could not cope with him being on dialysis, and became effectively homeless, until being settled in social housing.

Another interviewee described how his partner had taken the family monies, and then left him in considerable debt.

Financial capability before diagnosis and treatment

The extent to which people felt they had financial capability before they were diagnosed varied. When asked if they were able to deal with their finances on their own prior to receiving dialysis, some interviewees reported being well organised.

A key factor for these interviewees was that they had previously had no financial worries (were comfortable) because they had a regular income or were in a multiple income household. One interviewee reported he was very careful around his financial affairs, seeking out good deals and ensuring he was not victim to scams, he previously had worked in the insurance business, and was well paid. Others stated that they had always been careful with budgeting and household finances, as their incomes had always been modest and this enabled them to manage.

Examples of responses included:

"I was very organised with bill payments and managing money and was in full employment."

“I was in full time employment prior to dialysis and had no financial worries.”

“I was a forklift truck driver...I was good at budgeting and knowing what my income and outgoings were.”

One man proudly asserted his lifelong independence from any state benefits or financial support: “I’ve never had nothing given to me my whole life, so I didn’t expect anything.”

A number of the interviewees, including those who were on a modest income, or were sole earners in a household, reported seeking out good deals on their utility bills and budgeting carefully prior to receiving dialysis. This included, in several cases, paying bills by direct debit, which they set up prior to becoming ill, so they were clear that these were always paid. Pre-payment meters were also popular with interviewees, who were conscious of keeping track on a day to day basis of their gas and electricity expenditure.

Having a good income did not correlate with the individual patient being financially capable, however. In one case an interviewee clearly had no financial awareness and stated that she had a partner that was able to earn and support the patient financially and that he took care of all the family finances. This woman had been on dialysis for 22 years, and had brought up her children whilst receiving her regular treatments. There was no clear ‘before’ and ‘after’ dialysis situation for her, unlike others who had paid employment before diagnosis.

In another case, the patient stated she had a husband who worked, but it was unclear whether he supported her financially or not. He was barely referenced through the interview, and her sister and parents figured as the key supporting family members.

A further patient explained that her younger brother helped her budget for herself and her young daughter who lived with her in social housing. This woman was deaf, and her husband had left her some years previously, following the onset of her ill health.

Example 1: Male, 50

One couple who were interviewed together, as the patient spoke little English, reported that when the patient gave up his job as a photographer they had no income at all. They appeared to have no knowledge of how to claim welfare benefits or their entitlement to claim. Their mortgage fell into arrears, and they were unaware of where to go for help. “I was just crying one day and [the nurse] asked me why I was crying and I said 'my financial problem, I can't afford anything.'”

Following support from Auriga they claimed ESA and PIP, and managed to get a reduction in Council Tax, as well as a Blue Badge. They reported that things were tight still, but that they can now plan when they need to pay bills. “If it wasn’t for [Auriga staff member] my husband would probably have gone into depression...because of [Auriga staff member] everything has gone fine for us.”

Financial abuse

The onset of illness is certainly a time of great stress - both financial and emotional - for the individual diagnosed and their family. As noted above, the strain placed on relationships by one family member becoming dependent on another has led to several family breakups. The onset of illness appears to leave the individual open to abuse as they lose their job, become depressed and lacked the energy to deal with their household responsibilities including budgeting and bills.

Several of the interviewees had been subject to financial abuse either before diagnosis or at the point of diagnosis, or the early period of their treatment. One interviewee reported that their partner was taking the carers allowance for her care but was not caring for her. She was reliant on friends and family instead. Another reported that they had always left the financial planning to their wife, who when he became ill and unable to work, took all the household income, ran up debts on the family home, and then left him, taking his mobility scooter.

This group tended to be referred by clinical staff, in whom the patient would confide, or where the clinical team would recognise signs of physical and emotional stress in patients, and refer them for advice. In some cases a family member would refer them for help from Auriga. One patient was under the care of a Community Psychiatric Team, but none reported seeking advice outside of the project environment.

Attitudes to savings

Saving was an important factor for a number of the interviewees both before and during treatment. So whilst their income had changed, their priorities stayed the same. Help from Auriga was sought to maintain these priorities alongside their household essentials. Budgeting support from Auriga helped them to sustain their saving habit and in some cases their contribution to household income or for child maintenance.

One interviewee reported saving a considerable amount of money from a lifetime of work, which had been used to live on for four years after beginning renal dialysis. He proudly reported that he had not taken a penny from his two adult daughters who lived at home and both worked in professional jobs.

Another reported putting monies aside each month for his children, who lived with his ex-partner. The children were still at school, and he reported always paying for them from prior to receiving dialysis. This remained a priority for him in his budgeting after beginning dialysis, and he was able to do this through the support from the project.

One woman who lived with her adult sons had been supporting them through lean periods in their removal business, and again this remained a priority for her after being diagnosed as stage 5 renal failure (she had not started dialysis).

One interviewee reported "spending until its gone", having sold the family home following diagnosis. Illness appeared to have made him more spontaneous about his expenditure going forward, having previously been quite cautious with money.

None reported developing a new savings habit as a result of diagnosis. Those outside of the 'squeezed' sector, who had some household resilience, or regained it, welcomed the additional income to enable them to live a more fulfilling and independent life. One man discussed his

pleasure in buying some furnishings including a wardrobe and table for his new (social housing) flat. The awareness of time being limited appeared to play a part in their view of saving or choosing to spend. For example, a woman interviewed had been on dialysis for 22 years, and had sons close to leaving home. She wanted to spend time (and money) with them on a family holiday, linking this closely to the fact that she would not be able to have a kidney transplant again, which meant her life was entirely dependent on dialysis going forward.

Overall the indication was that savings were a priority for patients in the researched group. The survey of patients reviewed whether the respondent was putting aside monies for unexpected costs including utility bills, car repairs and replacing household items. Outside the control group, 73% indicated they put monies aside for utility bills, rising to 84% after the Auriga intervention, whilst 50% did this for unexpected household costs, rising to 70% after the intervention.

Managing utilities

Utility bills are a large household expenditure item and an area where Auriga had opportunities to help clients. People with renal failure spend considerable amounts of time at home, and sit or lie for long periods after treatment or when feeling ill, and can have high utility bills for keeping warm and clean. The initial survey (n= 152) reported that there were only around half (52%) who agreed or strongly agreed with the statement: *I plan ahead to make sure I have money to pay expected costs (such as utility bills)*. All interviewees either had a discussion with Auriga about switching supplier or changing tariff, and a majority had received some support to reducing their water bills in particular. Interviewees had little recall of receiving the fact sheets on utilities, but all interviewees remembered discussing energy costs and water bills with Auriga staff. The second survey did show an uplift in the number answering positively to this survey question. Using the same base of respondents between survey 1 and 2 (n=56) the percentage change was from 73% to 84% answering positively to the statement.

Typically, interviewees reported either already being on direct debit, and happy with this as a means of stabilising monthly bills, or using a pre-payment meter. The majority using pre-payment reported that they prefer it, as they can easily see what they use and manage their budget that way. Since 1st April 2017 the amount energy suppliers can charge a domestic prepayment customer is subject to a transitional price cap – this ‘safeguard tariff’ will reduce energy costs for those affected.

Others reported not needing support with utilities because household income was sufficient or they preferred their energy supplier ‘brand’. For example, one interviewee said he was a loyal customer of his energy provider, and did not wish to change, but that he has made a conscious effort to use less energy around the house since talking to Auriga. However, there were some interviewees who reported receiving help with managing debts to utility suppliers where they had run up arrears. In these cases an adviser from Auriga (who are members of the Institute of Money Advisers and hold the IMA Certificate in Money Advice Practice accreditation) would help them make more suitable payment plans to pay charges or arrears, change to a support tariff or access grant monies to pay off debts. All advisers are members of the Institute of Money Advisers (IMA) and hold the IMA Certificate in Money Advice Practice accreditation.

Example 2: Male, 79

One interviewee reported worrying about utility bills well before their diagnosis and treatment, but receiving no help until he was in contact with Auriga. This individual lived alone and was the oldest interviewee at 79. With support to change his energy tariff and get additional benefit income, he reported having new heaters put in each room and buying a winter coat and shoes. "I can pay the bills properly and I can more or less buy things for myself...like clothes and shoes. For the winter I bought a coat."

Dealing with benefit changes

Interviewees who had been 'just about managing' on the income they had, and without any means to develop any resilience to further financial trauma, were left in very difficult circumstances when they lost further income through benefit changes and reassessments.

The lack of an automatic transition from DLA to PIP, and the need for a new application had led the majority of interviewees to require help in claiming PIP, appealing PIP decisions, or going to Tribunal. A key issue with those who had run up debts, or had to borrow from their family, was losing DLA, leading to a sudden drop in income and potentially arrears. These people reported being turned down for PIP, or receiving a lower rate, making for an immediate change in their household finances.

The short turnaround time for PIP claims, and the complexity of the PIP claim process had confused a number of interviewees, and led to them missing the deadlines or receiving a much lower rate than they had on DLA prior to support from Auriga. One interviewee reported failure to get the higher rate for mobility - the 'enhanced rate' – and losing their vehicle at this point.

One interviewee had lost DLA and her husband had lost Carer's Allowance at the same time, and she had been supported through a Tribunal by Auriga to get these reinstated. Once they were reinstated she reports putting aside money for her special diet and plans out any additional expenses she needs.

Dealing with arrears

A small number of interviewees reported having issues with arrears. These were mainly related to council tax, rent or problems managing utility bills. Where arrears had built up, interviewees felt a high level of stress, and they coped with the arrears in different ways. One believed he would have had to leave his flat that was rented from the local council and make himself homeless, and another reported cutting right back on food to pay the arrears.

Interviews with Auriga staff confirmed that they routinely dealt with setting and rescheduling payment plans, or where there were considerable accumulated debts, the patient was referred internally to a specialist debt adviser (under a different project budget) or advised where debt advice services were available, such as; Citizens Advice, StepChange. Where there was a solution available to put a payment plan in place, welfare advisers arranged this, making weekly or monthly budgets manageable. Where debts were more serious, and involved intervention from the debt adviser, long term solutions such as declaring bankruptcy were considered amongst the options put to patients.

Other factors leading to arrears were; being wrongly assessed for Council Tax, through failure to claim a reduction for being disabled, and/or having a live in carer, and getting behind with their rent or mortgage.

Example 3: Male, 57

This interviewee had been having dialysis for 4 years and lived alone. He worked as a security doorman at weekends. The patient was not eligible for a kidney transplant due to his high BMI. He was working full time as a forklift driver before receiving dialysis but was not in full health. He was receiving tax credits and mobility allowance, and was good at budgeting and knowing what his income and outgoings were.

In 2017 he stopped receiving DLA and did not get PIP, and was struggling financially. He started getting into arrears and confided in unit staff who contacted Auriga. Auriga helped him get secure rails around the house to help with his mobility, a high chair in the kitchen for the patient to sit on whilst cooking, a fridge-freezer, and additional funding so he was able to afford money for a better diet to reduce his BMI. He was referred within Auriga for specialist advice which ultimately led to him declaring bankruptcy.

The patient had a token meter and was happy with this method of managing energy. Auriga helped him reduce his water bill costs. He began budgeting weekly and dividing his money amongst what he considers essential expenses e.g. kids who are still at school (living with his ex-wife), food and transport to his job and to the renal unit. He paid for additional help to do things around the house due to his mobility issues.

“[Without Auriga] I would have gone homeless because financially I wouldn’t have been able to survive. It was like they were angels sent from heaven.”

Changes to knowledge, skills and behaviour

Patients come into the healthcare system with a variety of previous experiences, and some are already very financially capable. They simply need some support to maximise their income and gain knowledge of the best deals available for household expenditure. They already have the skills in place to budget, and their behaviour did not need considerable modification. We could see those who had regained some equilibrium within their household budget returning to their previously organised ways of managing their money, eating a suitable and balanced diet and feeling more in control of their own lives. A number had returned to proactively putting monies aside for children and grandchildren from their budget.

Others have no experience of considering their household budget in terms of income and expenditure, either because they have never taken responsibility for household finances – a partner or other family member has done this for them - or because they have had sufficient income and had not felt they needed to actively budget. In a high proportion of cases both of these can be lost with the upheaval to relationships following diagnosis, plus the loss of their work related income.

Whilst a number of these interviewees were gaining greater knowledge of their entitlements and ways of managing their budget, as well as changing their behaviours with advice and support from

Auriga, only some of the interviewees envisaged having the confidence to manage independently. The survey showed that respondents would prefer specialist inputs on money or benefit problems, even after an uplift in their feeling that they were keeping track of their spending and feeling in control of their money. This is perhaps partially due to their high level of dependence on others due to their illness. It was also reported by interviewees to relate to the complex nature of product comparison, welfare benefits and dealing with a wide variety of providers of services, for which they had no energy or motivation even if they had the skills and confidence required. Low levels of digital confidence also inhibited their confidence in switching and assessing financial products. A longer term, more intensive intervention, involving mentoring and support would be required to build the confidence of this group. Working with their family and or support networks may also have been of benefit where they had these.

It is clear, that the process of gaining knowledge, moving to skills development and then to behaviour change is not a linear path or a given for all patients. For those patients who were the most ill, who were depressed, or who had very low personal resilience appeared to find dealing with the complexities of budgeting and product choice beyond their grasp. In this context, expecting behaviour change within the timescale of the project was unrealistic. Indeed, these patients may always need support, and will always be vulnerable due to their health condition, their prognosis, their age and factors such as lack of family support.

Example 4: Female, 38

This woman had pre-eclampsia which led to kidney failure and loss of a baby. She lived in a council property with her sister who is her full time carer and her 11-year-old son. Her mother comes and goes and is not a permanent resident, but was very supportive when she was diagnosed. Her husband was living abroad until recently and at the time of the interview she was 7 weeks pregnant.

Auriga encouraged her to get aids and adaptations from the local authority, carried out benefit checks, and were aiming to get carer support for her sister.

“They helped with my water scheme but I missed a payment...I have a memory problem. They are trying to get me onto it again. She asked if I get proper benefits and all that... I’m on ESA and disability. Child Benefit and Tax Credit.”

“I do get worried with bills. It’s so expensive. Groceries, TV licence, electric, water. £100/200 at a time it’s a lot. I use a pre-payment meter. My sister helps me, reminds me. I do direct debit, but I have to pay bills myself. If you want to go out you have to cut from here and there.”

“I would like to have a little bit financial stability. My son is starting a new school, they want expensive things at secondary school. It’s hard to say no then. I need a better property with a new baby, it’s not suitable.”

Increase in confidence

A number of the interviewees discussed their confidence in the future which was related to factors such as: having a close family or support network; having ambition to restart/start work; getting a kidney transplant; or supporting their children until they are older or in a better position to manage independently. Stabilising their income and household budget was reported as central to this increased confidence.

One man described how he had been in total denial of his illness, and had failed to home dialyse as a result. This led him to extreme illness, gangrene in his toes, and during this process his marriage broke up. His story is below:

Example 4: Male, 54

This man had been having dialysis for 3 years. He was diagnosed with pneumonia in 2013, then with kidney failure. He was diabetic and had 4 toes removed due to gangrene. He had home dialysis for one year which led to problems as his wife, couldn't cope with the dialysis and renal failure. It led to a divorce. They sold the family home for a low price to ensure the separation was quick. He stopped home dialysis and failed to get the treatment he needed due to the emotional turmoil he was in. He says he "lost the plot."

Auriga explained to him the various benefits available including PIP. Staff have also helped him apply for occupational health assessment for things around the home to help with fatigue, tiredness and balance issues including rails in the bathroom and around the home. He now receives funding to cover his transport costs. His taxi driver friend brings him to dialysis, picks him up afterwards, and they have lunch together to check he's recovered from his treatment. He then drops him at home again.

He said he was always able to manage his finances before his troubles began, and with the additional help and emotional support from Auriga, he felt confident about the future and was setting a monthly budget. He wrote his budget items down sometimes but mentally knew his income and what needed to be paid.

He believes his friends and his family have helped him "big time" through these difficulties, and is feeling optimistic about the future. He was using his savings to buy things for his new social housing flat. The patient hoped to go back to work and still had his taxi.

Reducing stress on patients by reducing their financial worries, and enabling patients to be clear about their income and budget appeared to go hand in hand with increasing their confidence.

A woman interviewed had been on dialysis for 22 years, and had her children whilst receiving dialysis. Her condition was hereditary. She lived with her husband and two sons. She was worrying about the fact her consultant would confirm she could not go back onto the kidney transplant list, having had one failed transplant, but that she was more confident since Auriga had supported her with her PIP application, reduced her water bills "a lot", and helped her with some aids for her deafness. She said this gave her and her husband, who manages the finances for the household, more confidence and reduced the stress on the family as a whole. She was looking to book a holiday in Benidorm where there is a dialysis unit next to the hotel, so she could spend time with her sons

who were growing up fast and wanted to do things with them before they left home. She was also thinking about getting a small dog who would sit on her lap whilst she rested.

Another man was very keen to get a kidney transplant, and was very much looking forward to getting back to work again as soon as he could. He said he would like to work until after retirement age, and was 62 at the time of his interview. He said he gets bored being at home with nothing to do. He lived in his own home with his two grown up daughters of whom he was very proud, and his wife who is a supply teacher. He is still able to drive his car and with the help of a Blue Badge, and PIP, feels he can retain some independence by driving himself to dialysis and to the shops etc. This interviewee was very confident with budgeting and had lived on savings for some time before claiming.

Conversely those who expressed the least confidence in the future had multiple problems converging (as did the other group) but were additionally depressed and lacked capacity to manage going forward. Their issues perhaps naturally also included a lack of financial confidence. They had usually had a relatively recent diagnosis, within the last year. They had family issues such as: divorce; financial abuse; being rejected by family members; attempted suicide; under the care of a community psychiatric team; living alone without care support; or were very ill and potentially in the terminal stages of illness. One felt that Auriga could not help them any further as their problems were too all encompassing, saying "I am lost, I am in the dark" several times.

They also tended not to have been in control of their personal finances prior to becoming ill, having relied on others to carry out the family budgeting, leaving them vulnerable if the family broke up. They tended to have no savings, and lived in social housing in most cases. These interviewees expressed a continued reliance on expert help from Auriga or similar as their main form of help to access their entitlements.

Impact on the mental and physical health of patients

The impact on the health of patients was clear to the renal unit staff who reported seeing, "a massive difference" (Unit Manager) in patients who had a project intervention.

Comments from unit staff included:

"Patients who receive additional income, especially for transport, are less stressed. There are positive changes also in patients who may be living alone and need help with arranging food." (Unit Deputy Manager)

"Patients are less stressed and happier which has a positive impact on their overall health since they are able to have additional support that makes their life easier." (Unit Manager)

"We have one patient who is blind and something like 'meals on wheels' was sorted...we saw improvements in her physical condition because she's been eating the right food." (Unit Deputy Manager)

Staff were very supportive of this service whereby patients access support, and learn skills in managing their finances, because the less stressed the patients are, the less difficult their life is: "It's a hard enough life as it is being on dialysis so you want to try and take away the other stresses as much as possible." (Unit Manager)

Having patients from a wide cross section of society enables health staff to refer to Auriga for targeted interventions when it is needed most, alleviating situations where a financial crisis or potential crisis is occurring. This was seen as a big plus, enabling them to provide a rounded and holistic on-site service for patients within the units.

IMD unit health impact

The IMD unit patients are significantly different in profile and needs from the renal patients. However, many issues are similar, and the reduction of stress amongst patients is a key clinical objective of using the Auriga service.

In the observed interview between advice workers and patients, the patient reported having been to Tribunal before regarding her benefits being withdrawn. She said, “it was very, very stressful...It’s the system that is wrong.”

In the IMD clinic it was reported that, “doctors are happy with this project and recognise that it alleviates the pressure off patients.”

Clinical staff report that there is lot less anxiety when a patients benefits have been sorted out. They believe a key issue for patients is PIP, as it changes and the disability of the patient is questioned. The rare and complex nature of the IMD variety of conditions were thought to be a barrier in getting PIP in place. Where it was granted, it was reported that patients and their families were much less stressed.

Change from baseline to follow up

The survey supports the finding that there were changes to the patient group as a result of project interventions, albeit within the limits of the methodology and sample noted elsewhere in this report.

There were 30 patients who, after an intervention from Auriga, either through the fact sheets or working with Auriga to improve their financial capability, had improved their score against the survey questions, suggesting an uplift in their confidence, skills and behaviours around financial capability. 26 patients did not change their score.

This can be compared to the 22 in the control group of patients had no personal intervention from Auriga staff, no fact sheets, and none of whom who had an improvement on their original score.

The improvement in scores ranged from 1-26, each score point represented by an uplift by one category in the Likert scale on one question in the survey. So for example a move from Strongly Disagree to Disagree is an uplift of 1 point. A change from Strongly Disagree to Agree is an uplift of 2 points and a change from Strongly Disagree to Strongly Agree is an uplift of 3 points.

The average scale of improvement was 4.1 across all questions. (It should be noted that a few survey responses showed a slight move downwards in score within this overall figure).

More details of the survey results are given in the following tables and in Annexes 6 and 7.

Table 1: Patients whose score on the Likert Scale changed between survey 1 and 2

	Changed score	Did not change
Control group (n=22)	0	22 (100%)
Not control (n=56)	30 (54%)	26 (46%)

Table 2: Changes from baseline to follow up

Question	Average overall score change	Control group change	Average scale of change in score
Percentage If I had debt or money problems I would seek advice and know where to get help	0.4	0	1.6
I have the skills and confidence to check if I am entitled to claim benefits	0.2	0	1.0
I talk openly and honestly to my friends and family about my money situation	0.2	0	1.1
I keep track of my spending and I feel in control of my money	0.1	0	0.8
I plan ahead to make sure I have money to pay expected costs (such as utility bills)	0.2	0	0.9
I plan ahead to make sure I have money to pay unexpected costs (such as car repairs or replacing household items)	0.3	0	1.5
I know how to get copies of my bank statements and I can understand them	0.1	0	0.8
I am able to use the internet when I need information and advice about money or benefits	0.2	0	1.0
I know about 'scams' and how to avoid them	0.2	0	1.0
I know how to shop around and compare best deals for at least two of the following: Gas/Electricity, Mobile phone/broadband, Credit cards, Bank accounts, Loans, Insurances, Food and groceries	0.2	0	0.7
I understand my energy bills and how to use my gas and electricity so I don't waste money	0.2	0	1.5
I am able to buy things that would help me to cope with my health condition (such as adaptations/aids or special dietary foods)	0.2	0	1.6
I don't often worry or feel stressed about my money situation	0.2	0	1.4
If I needed help with my money or benefit problems I would prefer to talk to a specialist advice worker	0.2	0	0.9

The table below presents this information by question showing the changes from baseline to follow up survey, excluding the control group and all respondents who did not complete both surveys, which is 56 people in total.

Table 3: Analysis of difference between respondents answering both survey 1 and 2 (excludes control group) (n=56)

Survey question	Survey 1 Agree or strongly agree with statement	Survey 2 Agree or strongly agree with statement	Percentage change
1. If I had debt or money problems I would seek advice and know where to get help	73	84	11
2. I have the skills and confidence to check if I am entitled to claim benefits	48	54	6
3. I talk openly and honestly to my friends and family about my money situation	64	70	5
4. I keep track of my spending and I feel in control of my money	77	82	5
5. I plan ahead to make sure I have money to pay expected costs (such as utility bills)	73	84	11
6. I plan ahead to make sure I have money to pay unexpected costs (such as car repairs or replacing household items)	50	70	20
7. I know how to get copies of my bank statements and I can understand them	88	93	5
8. I am able to use the internet when I need information and advice about money or benefits	30	36	5
9. I know about 'scams' and how to avoid them	55	64	9
10. I know how to shop around and compare best deals for at least two of the following: Gas/Electricity, Mobile phone/broadband, Credit cards, Bank accounts, Loans, Insurances, Food and groceries	48	50	2
11. I understand my energy bills and how to use my gas and electricity so I don't waste money	59	66	7
12. I am able to buy things that would help me to cope with my health condition (such as adaptations/aids or special dietary foods)	68	82	14
13. I don't often worry or feel stressed about my money situation	52	64	13
14. If I needed help with my money or benefit problems I would prefer to talk to a specialist advice worker	88	98	11

The pattern of responses is similar to the larger baseline survey results which can be view in Annexes 6 and 7.

Question 4 scores relatively highly at 77% of respondents, uplifting to 82%:

- **I keep track of my spending and I feel in control of my money**

However, stress about monetary issues is present in around half of respondents at 52%, reducing slightly by survey 2 to 64% (although the double negative in the logic of this question may have confused some respondents):

- **I don't often worry or feel stressed about my money situation**

Question 8 scores lower than all other questions at 30% uplifting only to 36%:

- **I am able to use the internet when I need information and advice about money or benefits**

This probably relates to the number of older respondents to the survey, as well as digital literacy issues.

Question 14 which suggests the need for specialist support scores highly:

- **If I needed help with my money or benefit problems, I would prefer to talk to a specialist advice worker**

Question 10 scores relatively low and shows little uplift (48 to 50%):

- **I know how to shop around and compare best deals for at least two of the following: Gas/Electricity, Mobile phone/broadband, Credit cards, Bank accounts, Loans, Insurances, Food and groceries**

However, planning for paying of energy bills and other expenses scores relatively higher with 73% agreeing with the statement uplifting to 84% by survey 2:

- **I plan ahead to make sure I have money to pay expected costs (such as utility bills)**

The difference between these two is probably related to the low level of confidence with the internet.

Question 6 which is also about planning ahead to pay for household items scores relatively lower, but does uplift from 50% to 70% of respondents by survey 2:

- **I plan ahead to make sure I have money to pay unexpected costs (such as car repairs or replacing household items)**

There is a relatively low score in survey 1 and 2 for question 2, echoing the specialist advice question above, although this does show slight uplift between the two surveys from 48% to 54%:

- **I have the skills and confidence to check if I am entitled to claim benefits**

There is a strong uplift in the question from 68% to 82% agreeing with the statement in question 12:

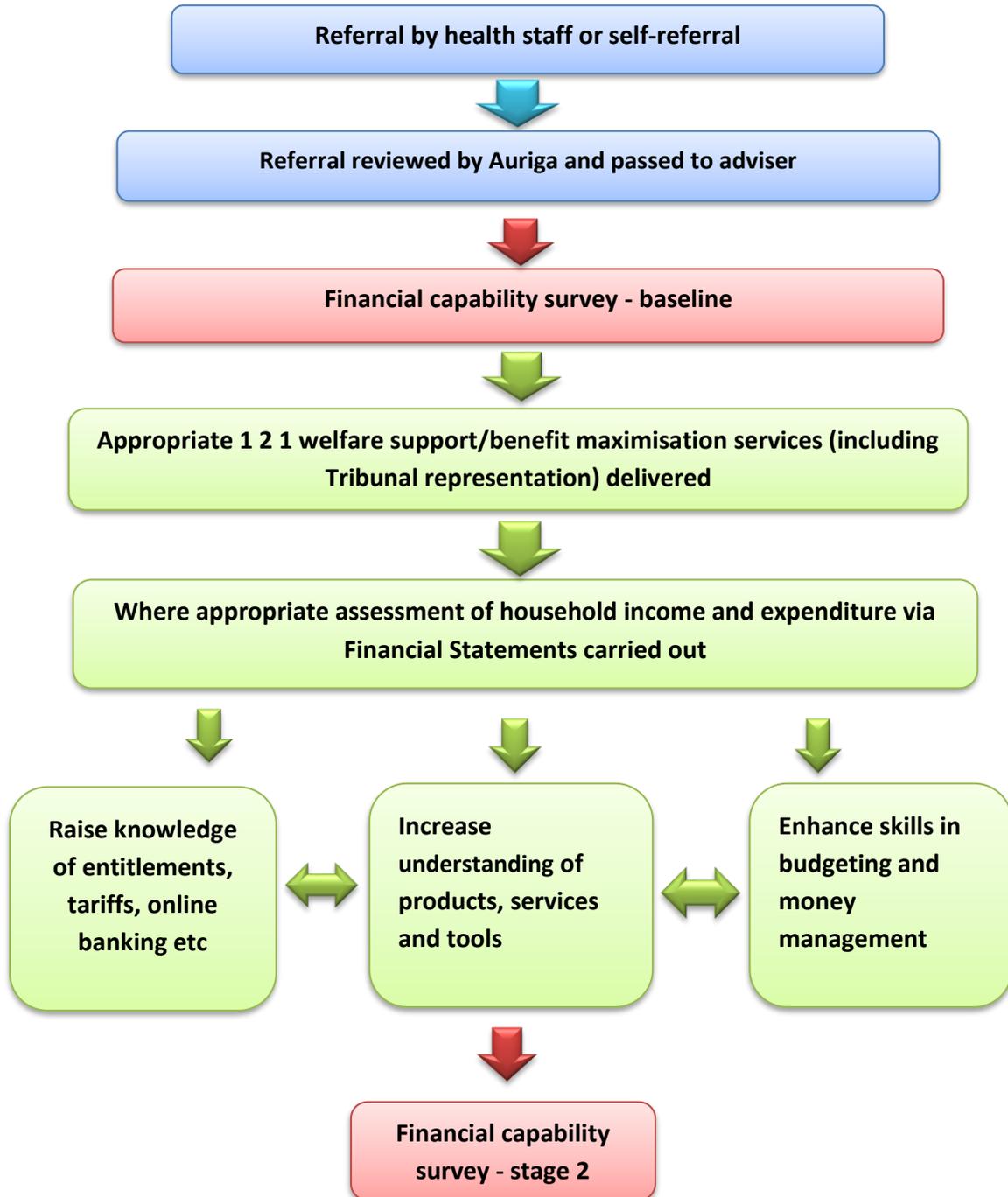
- **I am able to buy things that would help me to cope with my health condition (such as adaptations/aids or special dietary foods)**

The percentage changes in numbers agreeing or strongly agreeing with the statements in the survey from the baseline is interesting, but results from larger changes in score for a small number of respondents from within the 30 who changed scores. This means these results must be treated with caution.

Nevertheless, there is clearly a pattern of uplift across the board following the project intervention. This suggests that with more time and continued input more patients may increase their score, and possibly increase them by a higher amount.

4. Key findings: process evaluation

Diagram 1: The intervention process



Project delivery model

The delivery model used by the project is illustrated in the Diagram 1, and discussed in more detail below.

Interventions were delivered in healthcare settings with home visit being carried out when the patient wanted or needed support at home. Renal patients were routinely offered home visits if they had not begun dialysis or they were dialysing at home. The funding from the *What Works* fund allowed Auriga to expand services their services to offer home visits.

Initially the project planned to offer group workshops as a method to deliver money management activities, but feedback from healthcare staff indicated that group sessions were unlikely to be suitable or of interest to patients and alternative delivery methods should be offered. The rationale for this was that as renal patients had complex schedules of exhausting dialysis, and many consultant appointments, healthcare staff believed this model was unworkable for them. It was also felt that money management is a sensitive subject, and that patients would prefer not to have to discuss their views and capabilities in front of others. For IMD patients being at their clinic so infrequently, and being in medical meetings throughout most of their clinic visit, this model would not be a practical way of delivering the service for this group.

Evidence was collected from patients that demonstrated the lack of interest in group workshops and with support from MAS, the project delivery model was realigned, to provide individual one to one support to patients in the healthcare setting or at home.

It also proved difficult to deliver to promote the project to renal nursing staff within dialysis units in a timely manner due to staff being employed by external contractors. As part of the delivery model realignment it was agreed with support from MAS that the service would be promoted to renal nursing teams by Auriga's welfare benefit advisers who were based within renal units and IMD clinics rather than through staff team meetings. These advisers had already gained the confidence of staff and patients through their presence within the treatment centres and gave information on a one to one basis and via dissemination of an information fact-sheet. (This is a process Auriga is familiar and successful with, having been contracted to deliver these services across the West Midlands renal patient service.) Later in the project Auriga's welfare benefit advisers were able to deliver awareness sessions to matrons based at the dialysis unit within the Queen Elizabeth Hospital.

Through this route health care staff would then refer patients to Auriga where the patient had indicated to a staff member that they needed support, or where they could see patients were in need or in distress. Referrals were also accepted directly from patients who had chosen to self-refer. Once referred into Auriga services, the welfare worker would assess what the patient's situation was and take appropriate action to avert any impending crisis, maximise their income, thus supporting their health and welfare, and then move to develop patient financial awareness and build confidence of the patients in financial management and planning for the longer term.

Project delivery

The project team initiated a weekly or fortnightly presence (or more where there was a patient who needed urgent help) at renal units, and a bi-weekly presence at IMD clinics. Using this methodology plus home visits, the project worked with 409 renal and 73 IMD patients that were referred

between January 2017 and January 2018. During the term of the project 337 home visits were made for patients who preferred this method or who were unable to access help through other channels.

As seen in Diagram 1, welfare benefit advice staff would take referrals into the project though from healthcare staff or through self-referral. The team would then routinely carry out a benefit check to ensure that the patients were on the right benefits, and ensure they were claiming all they were entitled to, to maximise the income of the patients.

A wide variety of other interventions were carried out by the team related to the additional costs patients face, that supported their ongoing health and welfare. Interventions were to support:

- special diets
- taxis/transport costs to the renal units 3 times per week
- hospital parking costs
- additional heating at home due to periods of inactivity
- higher levels of water consumption especially if using home dialysis which takes considerable amounts of water
- aids and adaptations to the home to deal with increasing infirmity
- increased use of washing facilities to keep the home, clothes and body fresh and hygienic
- taxis to shops/home delivery for food at home
- additional costs for clothes to keep warm.

Specialist knowledge

The team routinely made grant applications for white goods where patients lacked facilities such as fridge freezers, washing machines and cookers. Advisers used their vast knowledge to source other appropriate grants or used the Turn2Us website. They were also able to get patients onto special utility schemes for vulnerable and disabled people, which are detailed in section 3. Patients were also assisted by make applications for grants for holidays. Many of the schemes and grant making charities used by Auriga are not well known amongst the general population.

This aspect of Auriga's project was designed to increase the knowledge and skills of patients, by making them aware of these additional sources of help and support. The survey respondents did show a strong preference to have specialist support for money or benefit problems (88% in survey 1 going up to 98% by survey 2) possibly because whole sections of the population are unaware and/or unconfident in claiming the right benefits, or using price comparison sites. The process of gaining support from Auriga had potentially confirmed the specialist nature of this work, given that the numbers preferring specialist support had increased by survey 2. This surveyed group's lack of confidence with digital comparison supports this view. The low levels of confidence in the numbers saying they knew how to shop around and compare best deals for in survey 1 and 2 also supports this conclusion.

Despite the survey conclusions regarding online activity, through this aspect of the delivery process, the team were improving a number of the patient's knowledge of, and connection to, financial products, services and tools. The work the team carried out certainly did increase the knowledge of a number of the patients regarding products and entitlements. For example, an interviewee stated: "I am not thick, but I had never heard of Carer's Allowance". Given that this is a state benefit which is covered on the www.gov.uk website and most major charitable websites for patients, general knowledge of the more specific schemes Auriga was offering for utilities, grants and aids and adaptations was considered very specialist knowledge by patients and staff within the units.

Working at the appropriate level to build financial awareness and confidence

The diversity of patients the Auriga team dealt with means that the Auriga team were very responsive to the capacity and capability of each individual. Where the individual patient was capable and confident to make contact and lead a process they let them do this with their support in the background. Where they did not have confidence or capacity, Auriga led and the patient was more strongly guided and supported.

Additionally, many of the schemes and processes Auriga utilise are specialist in nature, and interviewees do not know of the schemes prior to meeting with Auriga, or are unconfident in going through the processes of application by themselves. For example, one patient described how nervous she was in advance of her PIP interview in her home, having thought her DLA would just be transferred over. Having an Auriga adviser with her reassured her: "The [PIP interviewer] has never met me, knows nothing about me, and meets me for an hour. [The Auriga adviser] made sure it's all down right. She can only say what I've told her, but she makes sure it's all answered". This indicates the situation for the majority of patients interviewed in that they are capable of going through the process alone, but it causes them stress to do so, which is further detrimental to their health. The Auriga adviser is seen both as a support and a source of expertise in the process by the patient.

It is also the case that each patient who has been through any of the processes involved in the Auriga project, has gained experience and knowledge of how the system works, and what may be required in future. Hence, it is reasonable to assume patient's knowledge and skills are enhanced through the support from Auriga. For example, we might expect anyone who has been supported through the PIP process to be more confident and skilled in completing their PIP review each year as a result of the initial work with Auriga in gaining PIP. Further research into longer-term changes would be required to assess this, however.

Fact sheets

To support the development a greater knowledge and confidence amongst the patients, a set of fact sheets were produced on a number of household products and services. These aimed to help embed knowledge on financial services, products and tools. The fact sheets included:

- What is financial capability?
- Understanding your energy costs
- Saving energy in the home
- How to switch gas and electric
- Tariffs explained
- Protecting your money online

- Broadband switching
- Credit Unions, Post Office and Pensions
- Basic bank accounts
- Pay yourself first.

The fact sheets were routinely given to patients with whom the team were working. In addition, fact sheets were also used to make a specific intervention on financial capability for the MAS project. The baseline survey discussed above also facilitated identification of a cohort willing to have an advice session or simply a discussion about financial capability and how they wished to receive advice. The question in the survey was as below:

Table 5: Opt in to financial capability discussion

Would you be interested in learning more about money management and how to make your money go further? If so please tell us how you would prefer to receive advice and information by ticking a box below:	
Via a drop-in facility at a renal unit/QE hospital or a group session	
One - to - one	
Read a fact sheet or self-help pack	
Not interested	

As noted previously, patients did not indicate interest in drop in or group sessions which is an important point to note when working with these or similar patient groups in future. Advisers found that providing one to one advice on welfare benefits was an effective way of introducing more appropriate financial capability topics that were tailored to the need of the patient.

The fact sheets were given to those indicating a willingness to take part, and was followed by a discussion with one of the Auriga team on the topics within the fact sheets (as well as an advice session if welfare issues were uncovered). The follow up survey was then administered. Whilst the interviewees displayed little recall of the fact sheets or their contents, even when shown them as a reminder, typically interviewees could remember having a discussion with the Auriga staff member on key areas of covered by the fact sheets. This suggests that discussion of products and financial capability matters within the fact sheets was more effectively being covered as part of the overall process of welfare advice, rather than as a stand alone activity. This appears to be related to the very trusting relationship patients had with Auriga team members. Additionally, for those patients who had a real life situation necessitating making savings and budgeting more effectively the issues potentially had more impact.

Standard Financial Statement and budgeting

Another key point within the process of delivering welfare advice was use of the Standard Financial Statement (SFS), which has been used by Auriga since its launch in 2017. The SFS provides information on income and outgoings, monthly costs and any amounts owing (see Annex 5) and a routine aspect of the work of welfare advisers when applying for grants or making payment plans. To - date the SFS has worked well and is used alongside trigger figures held in Auriga’s case management system which help identify levels of monthly expenditure deemed reasonable when completing the SFS. This provided a prime opportunity for Auriga staff to engage clients in an overall

discussion about any difference in their household income and expenditure, and discuss the options to reduce expenditure through finding less expensive options or make savings in other ways.

This appeared to work as well or better than the fact sheets in prompting productive discussions on where household savings could be made, and making better decisions on utility suppliers, phone, broadband and TV contracts etc.

Example 6: Woman, 62

One adviser carried out a financial plan of income with a patient including benefits, weekly board from her children and outgoings e.g. food, electricity, heating, other household bills. The Financial Statement gave the patient and adviser an overview of her income and outgoings, enabling the adviser to secure a grant for tumble dryer. It highlighted a number of issues within her household budget that could then be addressed. Further support enabled her to secure PIP and a Council Tax rebate.

This patient had good financial capability, but stated that she hadn't been sure if she was getting the right benefits. "[I had] £84 per week. I was really struggling to live. My son does house removals you get a lot of dips and highs, there were getting to be a lot of dips at this time of year. There was very little left for food. I had applied for PIP and they refused me. [She cries]. We were living on beans on toast. It doesn't help my health condition, I need to be eating fruit and vegetables."

She reported that she felt "More financially stable with PIP. If the boys have a low in their income it's not such a concern. I feel a lot more relaxed with more money coming in. It's a lot off my mind. I haven't got the strength to get to the shops. All my money was going out on bills. Now I can order shopping online. I pay most bills by direct debit but I prefer to use pre-payments for gas and electric meters."

This patient now manages her own budget, and is taking responsibility for herself and her two sons who she helps financially, one of whom has sporadic work, and one who is bipolar.

This is an excellent example of the project's work in action. Initial contact is made via the medical staff who referred her for support. A Financial Statement is prepared, and it is clear that outgoings are outstripping income. Through a variety of means the patient's income is maximised, and the patient feels back in control of her life. She feels less stressed, better supported and is able to manage her household budget herself again. She likes to feel she can turn to the Auriga team again in future if she needs to. Her health has improved as she is less stressed, she can eat properly, heat the house to help her chest condition, and she has been able to get some aids and adaptations for her house making her physically safer at home. There would be no reason for her situation to deteriorate financially again, especially as she was financially capable before the crisis of becoming unemployed through ill health, losing her DLA and being turned down for PIP (unless her benefits were further reduced). With a stable income she was demonstrating clear budgeting on a weekly basis.

Increasing the financial resilience of patients for the longer term was the objective the team aimed to reach through the intervention process. By improving household income directly through additional benefits, or indirectly through help in kind, such as Blue Badge, grants and utility provider special tariffs, the project was able to move patients out of a crisis situation, enabling them to deal more rationally and thoughtfully with their future planning. In other words, enabling them to

expand their 'bandwidth', a key factor in developing financial wellbeing, as noted above¹⁸. It was clear that for some patients, reaching this point would take longer than the timescale of the project allowed.

Increasing resilience through non means tested benefits

Not all of the interviewees were in financial hardship ('struggling' group) or needed crisis intervention, however. The nature of some benefits such as PIP is that they are non-means tested. Auriga supported all patients who were referred to them whether they were in financial hardship or not. In these circumstances Auriga was able to support the patient to develop other wellbeing objectives, and reduce the displacement of family savings and income as a result of supporting all the expenses of the patient.

Example 5: Male, 62

For example, one patient had very good financial capability having been an insurance underwriter and had saved diligently throughout his life. However, his savings were insufficient to enable him to live until he could draw state pension at 67, in 5 year's time. He reported living on his savings for four years before asking Auriga for support. "Now my savings have run out. I didn't want to claim. I hate claiming. I paid all the bills for 4 years- didn't take a penny from my daughters. (One is a doctor, other is a transport analyst.) But now it's finished and the bills are still coming in.

I contacted Auriga to help with my PIP application. I tried for 45 minutes to get hold of the PIP team at the DWP. Auriga managed to get them on their mobile. They helped me get a Blue Badge...Insurance, petrol. It will help with that at least. I get tired when I walk. The Blue Badge makes it less of a pain when parking. Parking at the hospital is so expensive. (He has numerous appointments as he has had gangrene in his toes). I owe Auriga everything. If she says she will drop you a line tomorrow it comes then. I am just waiting for my kidney transplant. I will stop all these claims. I'll go back to work because I am a qualified loss adjuster. I can work from home. The job is there. There's plenty of work outside. If they give me a kidney today, tomorrow I will be back at work."

Where patients had savings or financial means, non-means tested benefits could still considerably enhance their life, giving this particular patient back a sense of independence, allowing him to drive without stress around the costs, and park for free for his medical appointments. It stopped him getting tired out when getting to and from the car, and enabled him to manage better with his damaged toes. His pride dictated that he did not ask for his daughters to help him, and retaining this was central to his sense of self. His outlook was very positive, and his ambition and desire was to return to work, and not to burden the state. The project was able to return him to an equilibrium, where he has support from PIP and is able to budget for his household whilst he waits to get back to his job. Hence this aspect of the projects work answered the third of the main research questions positively in that improving a patient's ability to manage money (knowledge, skills and attitudes) does appear to affect their wider physical and mental wellbeing.

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Right time, right messenger

Where the welfare advice was directly followed by income maximisation, and then more work on developing higher levels of financial capability the process was most effective. In some cases the advice work and financial capability work was being carried out concurrently, or independently of each other. This was dictated by the timing of the project work, given that the delivery model changed and survey amendments (see below for more detail). The process being delivered chronologically would give more time for those who needed more support in the longer term to make change to their knowledge, confidence and behaviours. As noted elsewhere, “It was also clear that providing the right type of information at the right time – and via the right messenger – is important, especially where people have experienced a financial shock.”¹⁹ The timing and delivery of advice and support is central to the success of any intervention to enhance financial wellbeing, and the advice workers from Auriga acted as the trusted individual from whom advice was sought and more likely to be heeded.

Patient trust in the service and the individuals delivering was apparent. The fact that the individuals had knowledge that staff and patients did not was an important success factor. Interviewees descriptions of their before and after welfare intervention implied significantly reduced stress in many cases: “without them I would have been on the streets”, or, “I owe everything to them”.

Praise for the individuals delivering the service and their work was unanimous amongst interviewees, except for one patient who stated that her problems were of a kind whereby Auriga could not help (family breakdown). Otherwise there were numerous examples of patients expressing gratitude and to the team. Their reliability in responding to requests for support was praised, in that: “if they say they will call, they call”. One interviewee expressed the need for more people like [the worker], because the need of patients like her, “are not recognised enough”.

Auriga’s unerring support was commented up by many respondents: Simple kindness and a friendly face was also an important factor: “I can just ring. I’ve never, never had that before”. Conversely, time was saved by the project having considerably inside knowledge and established contractual relationships with the relevant hospital trusts, as well as relationships with clinical and healthcare teams.

Project timeline

There were a number of initial delays in delivery of the project as it became clear that group and drop in sessions offered to patients were unworkable. There were also delays in providing project awareness sessions to contracted nursing staff to encourage meaningful referrals. These delays may have been mitigated if there had been more time to work with NHS facilitators prior to the project commencing. The IMD work also got off to a slow start as there was no history of working within this clinic and the service had to embed and become established, as the reputation with referral agencies and individuals was cultivated. This has all resulted in the project being more curtailed which was not desirable, especially where there is an objective to observe changes in behaviour and health gain which is a medium term change.

¹⁹ *Financial Capability and Wellbeing*, A qualitative report by TNS BMRB (March 2015)

The NHS context also provides challenges, with administrators and nursing staff being concerned that research on financial capability was potentially too intrusive for patients, or that it would overburden the patients given the number of surveys and questionnaires that come through the NHS itself. These challenges were overcome through a series of compromises on either side, including reducing the number of questions within the survey, and keeping demographic data collection to a minimum. These are issues to be taken into account in timing any health service intervention of this kind in future.

Once these issues were overcome, Auriga were able to 'hit the ground running', and quickly introduce new aspects to the services because they were well trusted within the renal units. Another provider would have to take time to establish this trust if the service were replicated elsewhere.

In addition, Auriga's direct relationships with utility providers enabled the team to deal quickly and effectively with most of the patients. Auriga's own switching site for utilities was also a helpful point of referral for those wanting to switch tariffs.

Cooperation between unit staff and Auriga

The project was premised on being able to work effectively within a healthcare setting to reach patients needing the service. This required a high degree of trust and mutual respect being established between the clinical staff and the advice team within each unit. The project team worked hard to develop this trust, and this was especially important in the IMD clinic where the Auriga service was newer than that in the renal units. The Auriga service within the renal units was already a trusted provider that was established within a contractual relationship with the hospital Trust.

The referral of patients into the system by clinical staff was central to the project's success, and is a good practice example of how advice services can be established in a healthcare setting through a high degree of cooperation and trust between the unit staff and the Auriga team. Referrals were made on the basis of observations and conversations between patients and unit staff. "Staff try very hard to make sure the patients know this service exists and is obtainable for everyone. If staff feel like there is anything that Auriga can potentially help a patient they will make a referral." (Unit Deputy Manager)

The ease of communication with the Auriga team was important to establish the service and provide patients with a sense of seamless provision: "[Patients] are here three times a week so obviously we're the only people they can talk to...so having Auriga to assist us ...the communication is just so easy because we can just refer straight away...if we are going to go with a social worker then it's like how many social workers do we have coming here...things just get addressed more quickly, obviously unless [Auriga] say it's not within their remit" (Unit Manager)

A key aspect of the establishment of the project in a healthcare setting was the ability to support clinical staff and patients through the project's work rather than be an additional burden to them. This had clearly been successfully managed, as unit staff were very appreciative of the work the team did, and their efficiency and effectiveness in delivery. They praised the model where the team

were on hand, but also the speed with which referrals took place, and the professionalism and expertise of the team.

Unit staff believed the scheme had been successful for them as staff, and had relieved them of an additional issue. This is central to any intervention in a healthcare setting, given the stretch on NHS services and budgets. “To have that expertise on hand it lessens the burden on us. They're the experts. The patients get the best information, the best service because they can get the expertise. They (Auriga) know exactly what's required to get the best outcome.” (Unit Manager)

Staff certainly wanted to retain the service: “I hope that the relationship with Auriga continues, I'd hate to lose that service. It's so nice for us to say 'well you know what I don't know but I know a person that can". (Unit Manager)

Dr. Clara Day, Consultant Nephrologist at UHB commented at the recent UK Care Conference:

“I have been looking after patients for a long time and through this work Auriga have gained the trust of patients and exposed social situations that I didn't know about”

“Of all the things that I have done for kidney patients this service has made the most difference to patients' lives”

“Working with Auriga has transformed the way we deal with our dialysis patients”

IMD process

In the IMD clinic the service was far less established at the outset of the project, and Auriga were new to the IMD clinic environment and clients. The level of trust between Auriga and the patients was harder to establish given the timespans between their visits to the clinic, and the physical distance the patients live from the clinic. Here much more groundwork had to be done to establish the presence of Auriga:

“Patient's weren't aware of services provided until they arrived for appointments so staff arranged for literature to be posted out to patients prior to the clinic session. This way patients were more aware and could arrive more prepared in terms of how we were able to help them.” (Auriga team)

The nature of the patient problems differed from the renal patients. IMD conditions are so rare that they have their own specialist support networks, charities and grant making bodies. Most of the families are in touch with these services.

In addition, as these conditions are lifelong, so the benefits of many of the IMD patients are established and in place: “Most patients have been suffering with related illnesses and diseases for most of their life and so will have grants and income/expenses etc. for living costs under control”.
Auriga team

However, where patients do experience problems, their own specialist support networks are not geared up to supporting them with the specialist knowledge and representation services that Auriga can provide: “There is not very much knowledge about these conditions and so it is very insular.

Patients can also get help and advice regarding benefits from relevant societies, but representation and more specialist advice isn't provided." (Auriga team)

The nature of IMD conditions also means that the Auriga's services have needed to adapt considerably to enable effective work with this group. Auriga lacked the long-term established relationship with unit staff and patients that exists in the renal clinics, as patients attend the clinic only once a year generally with their family or a carer. Patients have various different appointments when they attend the clinic and receive medical interventions of various kinds, meaning they are moving around the clinic throughout their visit. Referral to the Auriga staff member therefore had to be arranged in advance of their appointment, so the IMD unit team established a system of sending letters to each group of patients coming in the following week to say the service was available. From this letter of introduction to the services of the team, the patient or their carer/representative could call and ask for an appointment or ask for support when they arrived on a drop in basis. This system of sending out letters in advance considerably increased the flow of patients into the Auriga service.

One observation was carried in the IMD clinic of a referral for a tribunal from another agency. The patient had been sanctioned within the benefit system, and lost her benefits, and the case was proceeding to tribunal. Auriga was able to step in and take the case on. This indicated that the Auriga service was becoming better known, and was working cooperatively with other agencies as the service became established.

IMD clinic potential for financial capability awareness and development work

Given the newness of the IMD intervention, and the initial slow uptake, the IMD team worked closely with Auriga to increase the knowledge and acceptance of the services available.

All of these factors made the advice plus financial capability model of the project difficult for the Auriga team to deliver in the IMD clinic within the timescale of the project. Additionally, there was limited time available with each patient as they moved from one aspect of the clinic's service to another to deliver advice sessions covering anything other than urgent issues. The model of delivery was still being established and adapted to maximise its effectiveness during the evaluation. The Auriga team considered it was not yet proven that this was an appropriate or helpful context in which to deliver the additional financial capability components of the MAS project. For example, the fact sheets would have needed adaptation for patients with learning disabilities. The survey was also hard to administer for similar reasons, and because follow up with the patient to gain the second survey was not possible except by post or email.

However, this is not to say that in future, and with more time to establish, the financial capability elements could not be integrated into the project. One of the IMD unit staff thought that this would be appropriate with some additional planning: "We have patient groups, particularly PKU (phenylketonuria) and other conditions like that, where patients have a tendency to be a bit chaotic. They're not very good at being organised as a result of their condition...they are trying to be independent but struggle...potentially that [financial capability] could be very helpful. We have a Friday clinic where they come and spend the day without the medical appointments, and the PKU clinic would be a better place to offer financial capacity services." (IMD Unit staff member)

5. Limitations of the evaluation and future evaluation

Research within healthcare settings

The evaluation faced its challenges regarding research in a healthcare setting. The issues are both practical and ethical.

On a practical level, as noted in *Just what the doctor ordered: Welfare benefits advice and healthcare*, (Neil Bateman for Age Concern England 2008), “a key problem with measuring the impact of welfare benefits take-up on health is that by the time a person with health problems is seen by an adviser linked to a healthcare service, the damage to health may already have occurred...the health benefits of increased welfare benefits may be temporary or offset by ongoing, irreversible health deterioration.” Measuring any health gain resulting from welfare/financial advice and support becomes skewed or redundant in this situation, and renal failure or IMD, as long term, eventually fatal illnesses, are examples whereby there is an irreversible health condition. Supporting patients to gain additional skills and new behaviours can be offset by a deterioration of their condition.

In any event, measuring health gain is extremely problematic, as physical markers need very robust measures to assess before and after intervention. Research which potentially impacts directly on the health status of the individuals receiving medical interventions requires a control group and ethical approval. Even with these in place, it would be impossible to establish causality of any improvement in health, because the patient is in a place of medical treatment where numerous interventions and drugs are administered. Additionally, there are interactions with healthcare staff and other patients/family etc. which take place in this environment which also affect the patient’s health, mental wellbeing and ability to manage their medical, social and financial affairs. This evaluation indicated that positive experiences with all of these also impacted on the mental and physical health of the patient.

This suggests that the chosen method of self-reporting of feelings and changes by patients is a more realistic method to establish the impact of interventions in a healthcare setting, given the budget and timescale for the work. However, self-reporting of health and other indicators has its practical issues, in that patients feelings can change day to day, and recall of patients can be poor or faulty regarding health indicators. As health has many determinants, it was only possible to establish inferred relationships between welfare/financial capability advice and support interventions and any health gain reported.

Confidence and significance of the survey

The Auriga project integrated a survey of patients from the beginning of its work for MAS. This baseline survey acted as a mechanism to identify patients’ financial capabilities, and is therefore an interesting piece of research in its own right. The diverse nature of renal patients, who come from all walks of life, provides an interesting snapshot of the financial capability of the patient group.

Various tests can be run on these survey data to ascertain confidence intervals. In actuality these tests cannot show anything meaningful regarding the answers within the general population of renal patients. This relates to:

- The large size of the population group in question (circa 30,000 dialysis patients in the UK and 64,000 with kidney failure)
- The biases within the sample based on the fact that this was an opt in survey, and so may over represent people with some knowledge or interest in welfare and financial capability

The option of four answers within a Likert scale for each question, makes for too many variables in the answers. The high level of attrition, in both the overall sample and the control group, means that the data from the follow up survey in particular provides only an indication of the potential benefit of interventions with the renal patient population.

However, the initial sample of 152 can be regarded as a relatively robust sample that passes the simple 100 minimum interviewees advocated by 'rule of thumb' amongst statisticians. Coupled with the qualitative baseline data collected, the research provides some clear indicators regarding the knowledge, skills, behaviours and tools of patients, and their consequent financial capability.

The control group has also provided an interesting data set to look at alongside the main sample. However, the control group was subject to potential corrupting influences, as Auriga is a known presence within the renal units, and respondents within the control group may well have had influences upon them regarding Auriga's reputation and service. Therefore we cannot assume this group was 'clean'.

Comparing this study to known datasets

We can also increase the confidence in the results of the project by comparing existing research with the findings from the project evaluation. By assessing the extent to which the project cohort displayed the typical characteristics of the groups analysed within Financial Capability Surveys, we can confirm the extent to which the project cohorts display typical or divergent characteristics.

We know from MAS research work that someone's age and the financial wealth of their household appear to be the strongest determinants of capability across the dimensions. Independently of other factors, younger adults and people with access to the least financial wealth in their household are likely to be at greatest risk of detriment as a result of low financial capability across the dimensions.

Younger adults did feature within the project cohorts, especially within the IMD group. The financial capability issues that typify younger age groups include confidence, particularly amongst those aged 18 - 24, and 'live for today' attitudes (Financial capability survey 2015). However, the circumstances of most IMD patients is not like that of the majority of younger people, in that they have carers and are looked after by their family in most cases.

The high level of learning disability within this group also means that they are atypical of the Financial Capability Survey findings for young people. They are unlikely to have the ability to develop skills in financial capability in their lifetime. In fact the evaluation has been unable to work with sufficient IMD patients or their carers to gain a robust sense of the extent to which they display typical characteristics of this age group. However, the interviews with Auriga staff and IMD clinic team members confirms that for the youngest of their patients, the family is heavily involved, and is ensuring the young person is taken care of both their health and finances.

In relation to working age people, we know they are not well prepared for life changing events such as income loss with only just over one-quarter of the working-age population having a savings buffer equivalent to three months' income, and only just over half of families have life cover. We also know that the financial impacts of some life events can be so great that few people will ever have enough savings to cushion them from these impacts. Comparing these facts to this evaluation, we can see that this is indeed the case for this group. None referred to having been prepared for this life-changing event, and indeed several interviewees reported their diagnosis being a shock, and being totally unaware of their renal problem until they were diagnosed with renal failure. Some interviewees reported having a financial buffer from the past in the form of savings or monies from sale of assets. However, these resources had run out in one case and in another were being heavily drawn on.

In relation to older people research shows they tend to show good financial capability in many areas. They manage money well day to day but are well known for their brand loyalty and reluctance to switch providers. Older women have the greatest number of financial capability issues - they tend to live on low incomes, have the lowest skills and knowledge, and are least likely to shop around for better financial deals. The median age of renal patients is relatively high at 65, but the number of post retirement age people within the interviews was low, with only one in actual retirement, and another in semi-retirement. A number were in their 60's, and would not work again however. Certainly some of the older people interviewed were in particularly difficult circumstances, were living alone, and showed a low ability or motivation to change.

The project cohort was similar to people suffering sudden income loss through ill health, that have been studied on a global level²⁰, and within the UK by a number of insurance companies²¹, as well as organisations concerned with social welfare such as the Joseph Rowntree Trust²². For people suffering a sudden loss of income, the project cohort did not refer to having a buffer against ill health in a majority of cases. Occupational sickness schemes were not an option in most cases, as they had never worked in some cases, or where they had worked they had lost their job or resigned as a result of ill health. This led them to turn to state benefits, use their life savings, cut back on the household budget, and build arrears in rental or mortgage payments, household bills, rely on family support where this was available and build up debt on cards.

²⁰ Grant, U., *Health and Poverty Linkages: Perspectives of the chronically poor*, Background Paper for the Chronic Poverty Report 2008-09 (February 2005) Chronic Poverty Research Centre

²¹ *A high wire with no safety net: An analysis of the risks posed by sick leave on employee finances*, (2017) BHSF Employee Benefits Limited

²² *How does money influence health?* (2014) Joseph Rowntree Foundation

6. Implications and recommendations for policy and practice

The *What Works* Fund is particularly interested in the ‘struggling’ and ‘squeezed’ segments of the population and the project has some interesting findings related to the overall question the fund poses: *How can we help working age adults to improve their financial capability, develop budgeting and tracking habits, build up a savings buffer to withstand financial shocks and/or set financial goals for key life events?*

The socio-economic demographics of the target patient groups for the project, noted above, means patients with chronic health conditions are most likely to be drawn from the ‘squeezed’ section of the population, but will also be within the ‘struggling’ section, as a result of their illness affecting household income negatively. Additionally, a smaller proportion of patients represent ‘cushioned’ individuals because they are part of a more affluent household group. This project offered the opportunity to carry our research and interventions with a cross section of age groups and across MAS defined macro-segments within the overall patient population²³ offering insight into how effective financial capability interventions can be made in this and other healthcare settings.

The project worked across age ranges, including working age adults as well as those close to and post retirement. The renal patients in particular had suffered financial shocks at the point of diagnosis, leading to loss of employment, as well as through changes to benefit payments where their income had suddenly been stopped through benefit sanctions or in the change from DLA to PIP. In this sense they were an ideal group for the fund to consider and from which to determine if more financial capability work should be commissioned within the NHS.

The main research question the project itself posed was: *To what extent do interventions in a healthcare setting improve patient engagement with financial capability?* The table below summarises the factors that have been perceived as important for delivery in a healthcare setting that to be taken into account for any project or contract replication of the model by hospital trusts or grant making bodies.

Table 6: Requirements for working in a healthcare setting

Stage	Patient	Project staff	Requirements
Referral	Confidence of patient in the service by reputation or recommendation	Prompt response times from referral to first contact with patient	<ul style="list-style-type: none"> • Service embedded within healthcare unit/clinic through contract or other agreement with NHS administrators • Consultants and healthcare staff have confidence in the project team and their service for patients • Frontline healthcare staff have knowledge and understanding of referral process, and can quickly establish relationships with the project team

²³Market Segmentation: An overview (March 2016) MAS

Case management during crisis periods or to avert an immediate crisis	Trust building with case worker, building resilience, reduced stress, increasing 'bandwidth'	Maximisation of patient income, supporting reduction of stress and continued independence	<ul style="list-style-type: none"> • Welfare benefit knowledge • Tribunal expertise • Access to Trusts and Charitable grants • Knowledge of and access to referral routes for other appropriate support
Raising financial awareness of patient in medium term	Building financial awareness, understanding their new income and outgoings, managing their budget, continuing to build resilience	Presenting and discussing accessible information on tariffs and supporting product comparisons	<ul style="list-style-type: none"> • Knowledge of tariffs, tools and products available of potential benefit to the individual • Ability to engage patient beyond crisis intervention to support personal change
Building financial confidence of patients for longer term	Reviewing the best deals, confident budgeting and planning for the future, use of online tools, talking with family and friends about deals and products	Mentoring patient through switching energy providers, checking web based comparison sites, etc	<ul style="list-style-type: none"> • Time/skills to support patients establish behaviour changes • Contract/funding parameters sufficient to allow ongoing work with patients after immediate crisis averted • Patients consent/interest to work beyond immediate crisis period

The conclusions of the project are largely positive in relation to the research questions posed. Each research question is discussed in turn below.

Addressing financial capability in a healthcare setting

The research sub question posed was: *Are interventions in the healthcare setting improving patients understanding and knowledge of financial matters and helping them manage their money better?*

The healthcare setting certainly does offer significant opportunities for intervention in relation to financial matters with patients. Patients were able to draw on an advice service within a trusted and familiar environment. Healthcare staff emphasised the importance of having a service coterminous with other health interventions. Welfare advice and financial capability support delivered together is considered a strong working model, based on interviews with healthcare staff and patients.

The wide age range and demographics of patients allows access to groups that are difficult to reach in other contexts. Patients provide a cross section of society which enables health staff to refer for targeted interventions within their patient group. Healthcare staff are in an ideal position to judge when support is needed most, as they are alert to health and mental health changes within their patient groups. A trusted member of a healthcare team is often the first person to be approached where a crisis is pending or occurring for a patient. Where welfare advice staff have been

contracted to deliver support within the healthcare setting, this allows an easy referral route for healthcare staff to ensure patients are supported with financial issues as well as their physical health.

Gatekeepers can affect the ability to set services up in a healthcare environment, but once in place health teams are very ready to make referrals appropriately. The existing contracts for service provision that Auriga holds with hospital trusts helps build trust and appropriate referrals. For both the staff and patients within the healthcare setting, knowing that they have a welfare team on hand enables services to be offered in a holistic way covering health and welfare.

The support from medical staff for welfare advice within the context of the units and clinics considerably helps the referral in process, as well as ensuring patient actions are fully followed through. Additional awareness training for healthcare staff in working with welfare advice workers would help this process.

The timescale for the project was truncated due to a variety of factors including working with facilitators within the NHS and the pace at which NHS activities can be delivered, given the heavy administrative load and overall workload of staff. A learning point is that these factors should be anticipated within any project working within the NHS in the future.

In relation to whether interventions in the healthcare setting can improve patient's understanding and knowledge of financial matters and helping them manage their money better, this research indicates that with the right approach, welfare advice and support for money management can have a positive impact. Patients are in crisis in several ways when they first enter the dialysis process as a result of health, psychological and relationship matters all being under severe strain simultaneously. Financial crisis also follows in many cases. Having a mechanism to address this aspect of patient needs through welfare benefit advice on hand, and the wider support offered through the project, enables the crisis to be alleviated, and for more educational interventions around financial capability to begin.

Other patients who were not in crisis, but were planning for the future in order to manage their condition, the healthcare setting was also an appropriate and supportive environment to take action to address financial capability. These activities are best delivered alongside interventions to reduce the burden on patient finances through access to non means tested benefits, Blue Badges to prolong their mobility and independence, and support them with issues such as housing aids and adaptations and utility costs.

In all cases, having an advice worker on hand had proved effective, both in terms of alleviating poverty, supporting health and enabling independent living. Interviews and the survey of patients also indicate clear improvements in planning for both expected and unexpected costs as a result of the intervention.

Combining welfare benefits advice with financial capability interventions

The research sub-question posed was: *Is an immediate focus on welfare benefits and income an effective way of leveraging wider engagement in financial capability topics (e.g. budgeting and planning ahead, making better financial decisions)?*

The combination of welfare advice with financial capability work has proven successful in this context, in that welfare advice work, alongside the Standard (Common) Financial Statement, provides an ideal platform to discuss household budgeting. Within the established and trusting relationship between adviser and patient, within a familiar healthcare setting, suggestions, information and recommendations have considerable resonance with the patient. From this point of trust there can be a natural progression to discussion of budgeting and planning ahead, which can be difficult to initiate in other contexts due to their sensitivity.

Making better financial decisions and an openness to switching at least some service providers, opening bank accounts and ensuring value for money in utilities was exhibited by patients within this context. For a number of the patients it was clear they needed further mentoring to enable them to reach a higher level of financial confidence, but the change already exhibited within the project's patient groups does indicate that further support would build further confidence, at least in a proportion of the target population.

The process followed within the project intervention was also important in considering how to make longer term change within the target groups. The interventions often began through averting a crisis for an individual or family, although this was not always the case. Where the result of the intervention was that a crisis was averted or alleviated, this engendered considerable trust of the adviser by the patient, helped stabilise the individual in terms of mental health, and support their independence and maintenance of physical health (within the parameters of their overarching health condition). This opened the door to medium term work with the patient in discussing and supported them in making small behavioural changes and developing more financial confidence. For those who were not in crisis, the project was able to gain the trust of the patients by introducing them to non means tested benefits and other supporting actions such as gaining a Blue Badge, or grants for holidays. Again, this enabled the project team to discuss a much wider variety of topics with patients regarding the core aspects of financial capability, through fact sheets or simply chatting whilst patients were in treatment.

The delivery model could be adapted where there was more time available and potentially be more effective if welfare support advice was directly followed by income maximisation, and then more focus on developing higher levels of financial capability. In some cases this work has been carried out concurrently rather than in chronological due to project time limitations. The process being chronological in delivery could prove effective for those who need more mentoring and coaching support in the longer term to make change to their knowledge, confidence and behaviours.

Behaviour change is a medium to longer term change that individuals can make once they are out of any immediate health and psychological crisis resulting from diagnosis and the upheaval to their lifestyle. In future, this additional time should be factored in to allow behaviour change to embed and then be consolidated into longer-term patterns of behaviour.

Welfare advice staff can make interventions with patients in a structured way, to avert crisis, but renal and IMD patients are examples of groups that are being further pushed into financial hardship by changes within the benefit system. Both the patient groups considered were struggling with the definitions of disability being used for the PIP assessment, as well as the assessment itself, and this is a central aspect of advice work with these groups at this time. Online materials regarding PIP do not help these groups due to the lack of digital skills within the relevant sections of the population. Sanctions and loss of benefits are also significant issues for these groups meaning that crisis intervention will continue to be a central aspect of any service for patients absorbing time and money. Further review of the PIP/DLA changeover and its impact on patients would be helpful in the light of this.

Given that we know that a lack of resources affects financial capability over and above the impact of the scarce resource itself, these losses of income are further affecting the mental health and wellbeing of these patients. This suggests that financial capability work should continue to be combined with direct support in maintenance and maximisation of income to ensure loss of benefits does not become the overriding factor in all financial capability work with patient groups.

The effects of improving financial capability on health

The research question posed was: *Does improving a patient's ability to manage money (knowledge, skills and attitudes) affect their wider physical and mental wellbeing?*

Interventions to support patients with welfare benefits and financial capability are reported to save time and costs to the health sector, although the level of these savings cannot be estimated from this evaluation. They also appear to improve the wellbeing and confidence levels of patients.

Aids and adaptations in the home also support a healthy and safe environment within which people live, reducing the likelihood of falls. Support with gaining these aids for patients can deliver significant potential savings for the NHS, as well as considerably improving the health and wellbeing as well as the continuing independence of patients.

Having sufficient financial resources to enable budgeting to include proper meals for the special diets required by patients is central to patient health and wellbeing. Healthcare staff recognise this, but cannot make these interventions themselves which requires time and specialist skillsets. Improving the income of patients enables them to take responsibility for budgeting for their specific dietary needs.

Medical staff strongly support interventions within the healthcare system, at least at the front line of patient care. They clearly state that it alleviates stress amongst patients, reduces the burden on healthcare staff, enables advice they are not trained to give to be provided to patients, and supports healthcare goals such as a balanced, or condition appropriate diet.

The comments made by Dr. Clara Day, Consultant Nephrologist at UHB demonstrate the value of this type of support and advice service and the difference it makes to a patient's life.

This suggests that other NHS trusts should consider this project model to develop a more holistic service for other patients with chronic ill health.

Auriga recently had a presence at the National Renal Conference in Manchester where they spoke to delegates about the project and this has resulted in other NHS trusts making enquiries about the service.

Learning and sharing activity

The Sharing and Learning Plan (see Annex 4) has guided the activity of the project in this area.

Quarter by quarter of the project activities have included:

In quarter 1:

- Provision of monthly reporting for dissemination to NHS partners
- Provision of case studies for inclusion within quarterly reporting of KPI's
- We have exhibited and spoken at Renal Society Conference where we shared information and case studies.

In quarter 2:

- Provision of monthly reporting for dissemination to NHS partners
- Provision of case studies for inclusion within quarterly reporting of KPI's
- Auriga attended the National Renal Conference in Manchester to publicise the benefits of delivering welfare advice work alongside interventions to encourage financial resilience.
- In October Auriga exhibited at the 'Alstrom Society' event (one of the IMD group of conditions) about the project.
- Auriga delivered a 'workshop' to matrons of renal nursing teams to encourage meaningful referrals.

In quarter 3:

- Provision of quarterly reporting for dissemination to NHS partners.
- Provision of case studies for wider dissemination.
- On 13th September, Gay Hammett participated in MAS 'Engagement' Webinar and attended the MAS 'Learning & Sharing' event held in London on 10th November 17. This event gave the opportunity to share ideas, thoughts and experiences.
- On 16th November 17, the project lead and an adviser had a conference call with Sir Steve Webb, pension's commentator who was previously Liberal Democrat Member of Parliament for Northavon, who was interested to learn about the project.
- A representative from Auriga also attended the Money Advice Service 'Talk Money' Conference held in London on 16th November 17, and they were able to share our experiences of delivering the *What Works* Fund projects with other delegates.
- Auriga also supported Financial Capability week via social media.

In quarter 4 and ongoing:

- Provision of monthly reporting for dissemination to NHS partners
- Provision of case studies for inclusion within quarterly reporting of KPI's
- On 23rd January 2018, Gay Hammett participated in MAS 'Generating robust evidence' Webinar
- A representative from Auriga attended 'Utility Week' Debt Conference on 27th February 2018 and shared experiences of the project with other delegates
- Ongoing activities are outlined in Annex 4 as part of our Learning and Sharing Plan
- On 25th April 2018, Auriga held a 'UK Care' Conference that brought together representatives from energy companies, water companies, Charitable Trusts and University Hospitals Birmingham where experiences of the project were shared

UK Care conference

The object of the 'UK Care' initiative is to provide a welfare support and income maximisation service to all dialysis patients throughout the UK that is free of charge to the NHS. Services will be based on the model currently being delivered by Auriga that will incorporate learnings from the *What Works* Fund project.

The aim of the conference was to form a collaboration of partners who will work together and combine their resources to fund the service.

Delegates included representatives from:

- 19 different energy and water companies
- Money Advice Service "What Works Fund"
- University Hospitals Birmingham
- Severn Trent Trust Fund
- United Utilities Trust Fund
- Consumer Council for Water
- Kidney Care UK

The conference elicited positive support for the 'UK Care' concept with 15 representatives showing an interest in being involved in a steering group.

Annex 1: Patient Survey Example

Auriga have been working with renal patients for the last 12 months to deliver a personalised money and welfare benefit support service. Our services are free and confidential.

We would like to hear from you so we can gain further insight into the financial and welfare benefit issues being faced by patients and learn how we can provide our advice and support more effectively.

Taking part is completely up to you.

We can assure you that the information you provide will remain confidential and we will not pass your details onto anyone or use your name in our reports.

Your access to any help or support provided by Auriga will not be affected, whether you take part or not.

The questionnaire will take about 5 minutes to complete.

We hope you will be willing for us to contact you in the future so we can complete our evaluation. Please tick one or more of the boxes below so we know how you would prefer to be contacted:

By telephone	
By email	
At a renal unit	
At home	
I do not wish to be contacted	

Your help is much appreciated.

If you wish to have more information about the service provided by Auriga please contact us on 0800 111 4894 or speak to a member of your renal team who will make a referral on your behalf.

Name				
Address				
Telephone no.				
Email address				
Age (please tick)	Under 20 yrs	20 - 40 yrs	41 - 60 yrs	Over 60 yrs

Please tick the boxes that apply to you	
I am a patient at a renal clinic but not receiving dialysis or had a renal transplant	
I am receiving dialysis at a renal unit or at the Queen Elizabeth Hospital	
I am receiving dialysis at home	

How long have you been under the care of the renal team?	Please tick the box that applies to you
Under a year	
Between 1 year – 5 years	
Over 6 years	

Please read the following statements and answer as honestly as you can by ticking the appropriate box

	Strongly Disagree	Disagree	Agree	Strongly Agree
If I had debt or money problems I would seek advice and know where to get help				
I have the skills and confidence to check if I am entitled to claim benefits				
I talk openly and honestly to my friends and family about my money situation				
I keep track of my spending and I feel in control of my money				
I plan ahead to make sure I have money to pay expected costs (such as utility bills)				
I plan ahead to make sure I have money to pay unexpected costs (such as car repairs or replacing household items)				
I know how to get copies of my bank statements and I can understand them				
I am able to use the internet when I need information and advice about money or benefits				
I know about 'scams' and how to avoid them				

Please read the following statements and answer as honestly as you can by ticking the appropriate box

	Strongly Disagree	Disagree	Agree	Strongly Agree
I know how to shop around and compare best deals for at least two of the following: <ul style="list-style-type: none"> - Gas/Electricity - Mobile phone/broadband - Credit cards - Bank accounts - Loans - Insurances - Food and groceries 				
I understand my energy bills and how to use my gas and electricity so I don't waste money				
I am able to buy things that would help me to cope with my health condition (such as adaptations/aids or special dietary foods)				
I don't often worry or feel stressed about my money situation				
If I needed help with my money or benefit problems I would prefer to talk to a specialist advice worker				

Would you be interested in learning more about money management and how to make your money go further? If so please tell us how you would prefer to receive advice and information by ticking a box below:

Via a drop-in facility at a renal unit/QE hospital or a group session	
One - to - one	
Read a fact sheet or self-help pack	
Not interested	

Thank you for taking the time to complete this questionnaire. If you wish to ask any questions please contact us on: 0800 111 4894.

Annex 2: Theory of Change

THEORY OF CHANGE

FINANCIAL VULNERABILITY & LONG TERM ILLNESS: PROVIDING AN EFFECTIVE MONEY & WELFARE ADVICE SERVICE

CONTEXT

- 1. Context: Patients with a long-term conditions face poor financial outcomes and a significantly low wellbeing. They require close integration between care, medical treatment and money & welfare support service.*
- 2. Our final aim: To provide evidence that patients with long term illnesses benefit from more in-depth support, in appropriate locations, to achieve an improvement their financial wellbeing.*
- 3. To deliver this we are specifically trying to achieve:*
 - (i) A clear understanding of the financial pressures of patients with long-term conditions*
 - (ii) An improvement in the financial capability outcomes of patients suffering from long term illness, and*
 - (iii) An assessment of the extent to which the particular financial needs of patients are addressed by the service.*

INPUTS	ACTIVITIES	OUTPUTS & KPIs	OUTCOMES	IMPACT
<p>Promotion and referrals from staff who care for patients in the NHS units for Renal Services and Inherited Metabolic Disorders.</p> <p>Cost of service in terms of design, administration, delivery and evaluation of money & welfare advice for patients.</p> <p>Staff skills and knowledge administering, delivering and evaluating the service, engaging with patients and stakeholders.</p> <p>Access and availability of venues to deliver the service and</p>	<p>Provision of money & welfare advice by advisors through a variety of channels and in a range of locations and venues.</p> <p>Materials to support advice and workshops.</p> <p>Provision of training to staff at units about identifying need and effective referrals.</p> <p>Collection of knowledge and evidence about the financial pressures and needs of patients with long-term health conditions.</p> <p>Collection of data and evidence about the effectiveness of</p>	<ul style="list-style-type: none"> - Number of advisors working with patients - Number of patient referrals - Unit location and date of referral - Patient details and characteristics - Types and locations of contact - Number of individual benefit checks completed - Number of individuals receiving in depth 'expanded' assistances (e.g. minimising expenditure, review of attitudes towards money) - Number of patient workshops - Case actions/support provided e.g. blue badge, benefit check, occupational therapy etc. - Referrals to other support services (e.g. grants) - Number of staff trained in identifying needs and effective referrals <p>Number of patients who received help and:</p> <ul style="list-style-type: none"> - know where to go for advice, guidance and tools about their financial situation, in person, by phone and using digital resources - proactively seek advice and guidance - maximise income (e.g. claiming a benefit(s)) - have the physical ability to access appropriate financial products which meet their needs via appropriate channels - have the technical ability to access financial advice, guidance and tools which meet their needs in a form and language they can understand, and channel they can use effectively - talk openly and honestly about money with advisor, family or friends - anticipate and plan for less positive scenarios (e.g. planning for care costs) - are motivated to keep track of their finances 	<p>The patient is...</p> <ul style="list-style-type: none"> - Able to understand benefits entitlement - Accessing a wide range of benefits and grants - Accessing and using financial products and services, such as bank accounts and money advice. <p>The patient has...</p> <ul style="list-style-type: none"> - Maximised their welfare allowances - Less debt - A positive attitude, is motivated and has goals in relation to money - Increased general wellbeing <p>Estimates of NHS service prevented a result of patients improved wellbeing.</p> <p>Staff are aware how to identify needs and make an effective referral.</p>	<p>Patients suffering from long term illness have improved their financial capability as a result of more in-depth support.</p> <p>There is a reduced likelihood of patients suffering from anxiety and depression.</p> <p>Patients suffering from long term illness have improved psychological wellbeing.</p> <p>Patients have been given confidence to use skills.</p>

<p>assistance to individuals.</p> <p>Relationship with other organisations including; MAS, UHB renal services, IMD unit.</p> <p>To build relationship and trust with the patient</p>	<p>the service in terms of improving financial capability and wellbeing.</p> <p>Help and guidance to build confidence levels to use skills for the future</p>	<ul style="list-style-type: none"> - feel in control of their financial situation - have confidence in their approach to budgeting - feel their psychological wellbeing has improved; they have lower levels of mental stress and lower likelihood of suffering from anxiety and depression. <p>Have the confidence to use skills and knowledge learnt and realise the positive outcomes it can produce</p>	<p>Auriga has improved and shared knowledge about the financial pressures and needs of patients with long-term health conditions.</p> <p>Testing the assumption that working with patients, not only giving them skills and knowledge but the confidence to use what is learnt.</p>	<p>Cost savings to the NHS.</p> <p>Patients have a more positive mind set and outlook.</p>
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Annex 3: Consent form for interview

Information Sheet and Consent Form for patients attending Renal Service Units and with Inherited Metabolic Disorders on the evaluation of the Auriga MAS project

Carolyn Hay is an independent researcher who is carrying out an evaluation on behalf of Auriga services. She is asking people some questions about receiving support from Auriga. This information will help her understand what difference Auriga's help and support has made to you.

Why am I being invited to take part?

The research will help us understand what is working best, so we can improve the support available to yourself and others.

What will it involve?

Carolyn will discuss a number of questions with you, and talk about your experiences. The decision about what to share is yours.

Do I have to take part?

Your participation in this research is voluntary and won't affect your treatment or services.

What will happen to the information I give?

Information such as your name, your family or friend's names, will not be kept. Your information will be confidential and destroyed at the end of the research.

Any questions?

If you have any questions, please feel free to ask.

Consent form

You have been invited to take part in the evaluation of the above project. You have been given the Information Sheet so you can understand what this involves. If you agree to take part, please read and sign this consent form. Many thanks.

1. I have read the Privacy Information Sheet, or it has been read to me and I understand it.
2. I understand that anonymised data will be used by the evaluator and Auriga to develop a report.
3. I consent voluntarily to be a participant in the evaluation but can withdraw my consent at any time.

Please print your name:	
Please sign here:	
Date:	
For office use only: Unique Reference Number (URN)	
For office use only: Treatment Unit	

Annex 4: Learning and Sharing Plan

It is important to take time out to plan the way that you will learn from your evaluation, and how you will share that learning with others. The best way to do this is to think about **why** the information is needed, **what** that information looks like, **who** needs to know it, and **when and how** they need to know it. You should do this when you start to think about your evaluation because it will influence the approach you take, but you should keep your plan at the front of your mind so that it can evolve over time.

Use this template to work through the key stakeholders for your evaluation, whether they are internal or external – and their needs.

Published outputs are subject to quality assurance by the Evaluation and Learning Partner; they will also have an oversight in terms of what's disseminated to who.

**NAME OF PROGRAMME BEING EVALUATED:
A WELFARE AND MONEY ADVICE SERVICE FOR PATIENTS AFFECTED BY LONG TERM ILLNESS**

Who needs to know?	Why is the information needed? What will it be used for?	What is the information?	When is the information needed?	How should the information be supplied? In what format?	Action: who will be responsible for delivering this?
Trustees and Senior Managers Team at Auriga Services	To inform decisions about delivering similar schemes in the future	Outcomes measurement showing impact on people with <ul style="list-style-type: none"> - A long term condition - In financial difficulties 	Quarterly/monthly reports during term Evaluation report May / June 2018	Presenting to Trustees Presenting to SMT	Name of person Mark Abrams
Bid Writer writing grant applications	To feed into <ul style="list-style-type: none"> - grant applications for further funding - tenders for other work 	Outcomes measurement showing impact on people with long term conditions Evidence to show that the scheme is effective at engaging people in financial difficulties to improve their financial capability	quarterly/monthly reporting of KPIs	Example: Evaluation report Key findings document	Name of person Carol Arnold/ Rachael Bestwick
Programme development team	To better understand the needs of people engaged by the scheme, so we can refine the activities we deliver	Findings from case study work with people with long term health conditions to understand their pressures and needs	Quarterly/monthly reporting of KPIs monthly team meetings	Case studies Evaluation report /key findings document	Name of person Mark Smith/Stewart Hill
University Hospitals Birmingham NHS Foundation Trust	In particular, the <ul style="list-style-type: none"> - Quality of the support - Value for money 	Feedback from patients Key Performance Indicator data collected by Auriga	Quarterly/monthly reporting of KPIs and monthly progress meetings at start of contract	Review of Key Performance Indicator data collected by us on a quarterly/monthly basis Centres	Dr Clara Day

	<ul style="list-style-type: none"> - Advantages of home based provision - The financial capability developed throughout the course of the work. 			Dissemination of key findings via appropriate event(s)	
The West Midlands Renal Network	What can be learned for an expansion of any similar services	<p>Outcomes measurement showing impact on people with</p> <ul style="list-style-type: none"> - A long term condition - In financial difficulties 	Evaluation report May / June 2018	Dissemination of key findings via appropriate event(s)	Dr Clara Day
Staff in Renal Centres Staff in IMD Service	<p>To examine this approach in detail, see if it</p> <ul style="list-style-type: none"> - Has a valuable role to play in holistic patient care - Enables local teams to respond to the different needs of different patients - if engagement and referral is working effectively – if the most vulnerable people are accessing the service 	<p>Feedback from patients</p> <p>Key Performance Indicator data collected by Auriga</p>	Ongoing progress meetings	Key findings document	Dr Clara Day Dr Howit NHS Group Manager Nursing Staff
Kidney Care UK previously BKPA (UK's kidney patient support charity)	To see if it would be beneficial to roll the scheme out more widely	Outcomes measurement showing impact on people with Chronic Kidney Disease	Ongoing Evaluation report May / June 2018	Dissemination of key findings via appropriate event(s)	Paul Bristow

CLIMB UKs Inherited Metabolic Disorder support charity (IMD)	To see if it would be beneficial to roll the scheme out more widely	Outcomes measurement showing impact on people with Inherited Metabolic Disorder		Dissemination of key findings via appropriate event(s)	
The Institute of Money Advisers (IMA)	Sharing best practice on financial capability with professionals across the UK	Outcome data showing impact on people in financial difficulties	2-3 times throughout the year and in April 2018	Communication about findings during and at evaluation phase <ul style="list-style-type: none"> - Social media - Facebook - Twitter and a blog on our new website 	
The Money Advice Liaison Group of the United Kingdom (known as MALG) And regional discussion forum	Sharing best practice on financial capability across the network	Outcome data showing impact on people in financial difficulties	2-3 times throughout the year and post evaluation May/June 2018	Communication about findings during and at evaluation phase <ul style="list-style-type: none"> - Social media - Facebook - Twitter and a blog on our new website Dissemination/discussion at a regional forum	info@malg.org.uk Chair, Liz Barclay
Social Enterprise UK	Outcomes sharing	Outcome data for policy work	May / June 2018	Communication about findings	Peter Holbrook
Auriga - UK Care Conference	Outcomes sharing	Outcomes and impact of work	April 2018	Sharing project experiences as part of presentations	Mark Abrams
UK Care steering groups	Encouraging engagement Outcomes sharing/ benefits for partners	Outcomes measurement showing impact on people with long term conditions. Evidence to show potential partner benefits	June / July 2018 ongoing	Dissemination of key findings Presentations to steering group	Mark Abrams / Carol Arnold

Annex 5: Financial Statement Example

Name: _____
Date of Birth: _____
Application: _____
Partner: (if applicable) _____
Partner D.O.B: (if applicable) _____

Address: _____
Dependent children: Under _____
Other dependents: 0 _____

Number in household: 1 _____
Number of vehicles in household: 0 _____
Housing Tenure: [Not Specified] _____
Please confirm you have considered (or discussed with an adviser) the use of any assets to make lump sum payments



Contact/Team Name: Nicola Turner
Agency: Auriga Services
Agency Address: Auriga Debt Advice
 PO Box 8778
 Sutton Coldfield
 B72 1TJ
Membership code number: 12884546
Case reference number: 2696140
Date of statement: 29/01/2018
Date of review: 29/07/2018
Employment: _____
Client: [Not Specified]
Partner: _____

Overview	Amount (£)
Total Income	£1,678.60
Total Outgoings	£1,654.63
(Income - outgoings)	£23.97
(Saving contribution)	£0.00
Debt admin fee (if applicable)	£0.00
Total available for priority creditors	£23.97
Total available for non-priority creditors	£23.97
Monthly Income	
Earnings	£867.10
Benefits and tax credits	£811.50
Pensions	£0.00
Other income	£0.00
Total Income	£1,678.60
Monthly Outgoings: Fixed Costs	
Home and contents	£428.97
Utilities	£130.00
Water	£28.34
Care and health costs	£421.98
Transport and travel	£260.00
School costs	£0.00
Pensions and insurances	£5.00
Professional costs	£0.00
Other essential costs	£0.00
Total fixed costs	£1,274.29
Monthly Outgoings: Flexible Costs	
Communications and leisure	£68.34
Food and housekeeping	£303.33
Personal costs	£8.67
Total flexible costs	£380.34
Total monthly outgoings (fixed and flexible)	£1,654.63
Savings	£0.00

Please confirm that a monthly contribution to savings has been considered (or discussed with an adviser)

Additional Notes:
 Reasons for debt, client circumstances or vulnerabilities, temporary situations, detail regarding benefits or repayment terms:

Notes:
 Electricity: pre payment
 Other travel (e.g. taxis): Includes Taxi's to Dialysis
 Food and housekeeping: specific dialysis diet

Annex 6: Survey commentary

The baseline survey was completed by 152 people including the control group consisting of 41 people. The demographic data collected were their ages; and their time on dialysis was also collected.

Age	Count	Percentage
0-19	1	0.7
20-40	18	12
41-60	51	34
61+	74	49
Not provided	8	5
Total	152	100.0

Time on dialysis	Count	Percentage
Under 1 year	32	21.1
1-5 years	76	50.0
Over 6 years	37	24.3
Not specified	7	4.6
Total	152	100.0

The control group consisted of 41 people who opted into the survey. The control group demographic was similar to that of the main sample.

Control group

Age	Count	Percent age
0-19	0	0
20-40	4	10
41-60	10	24
61+	22	54
Not provided	5	12
Total	41	100

Survey 1: Baseline results

As the survey used a Likert Scale to collect answers, it was not possible to discern clear patterns with the sample size achieved. Therefore, we have grouped Agree and Strongly Disagree into one percentage to allow clearer results patterns to emerge. The full analysis of answers by question are given in Annex 7.

Baseline Survey: Agree/Strongly Agree with the statement

Question	Percentage score agree or strongly agree with statement	Agree or strongly agree with statement in numbers
If I had debt or money problems I would seek advice and know where to get help	44%	66
I have the skills and confidence to check if I am entitled to claim benefits	33%	51
I talk openly and honestly to my friends and family about my money situation	37%	56
I keep track of my spending and I feel in control of my money	53%	81
I plan ahead to make sure I have money to pay expected costs (such as utility bills)	52%	80
I plan ahead to make sure I have money to pay unexpected costs (such as car repairs or replacing household items)	43%	65
I know how to get copies of my bank statements and I can understand them	58%	88
I am able to use the internet when I need information and advice about money or benefits	25%	38
I know about 'scams' and how to avoid them	44%	66
I know how to shop around and compare best deals for at least two of the following: Gas/Electricity, Mobile phone/broadband, Credit cards, Bank accounts, Loans, Insurances, Food and groceries	34%	52
I understand my energy bills and how to use my gas and electricity so I don't waste money	45%	68
I am able to buy things that would help me to cope with my health condition (such as adaptations/aids or special dietary foods)	48%	74
I don't often worry or feel stressed about my money situation	41%	63
If I needed help with my money or benefit problems I would prefer to talk to a specialist advice worker	59%	89

Survey 2: follow up

The number who completed both the first and the second, follow-up survey, was 78 including 22 from the control group.

The attrition rate was 48%. The attrition rates were related to the following factors recorded against each non return by number of patients:

- patients no longer wishing to participate further in the study (10)
- the survey being posted to the patient, and not being returned (26)
- patients who initially completed the survey dying before return of the second survey (6)
- the patient not being reapproached due to being in very poor health (10)
- patients receiving a transplant, and no longer being at the survey site (3)
- patients moving home or being out of the country for a long term (2)
- patients lacking the capacity to participate further through lack of a translator or a disability and no ability to administer the follow up in these circumstances (11)
- patients not attending clinics regularly enough to collect the follow up survey (3)
- times at unit being inconsistent, and the survey administrator being unable to catch up with the patient (4)

The control group

The control group consisted of 22 people who opted to return both the first and the second survey. This group received no advice from the Auriga team. The size of the control group and the overall survey sample size for survey 2 means that no significance can realistically be attached to the control group data.

Details of the control group and changes between survey 1 and 2 are given in the table below:

Table 4: Control group results

	Changed score	Did not change
Control group (n=22)	0	22 (100%)
Not control (n=56)	30 (54%)	26 (46%)

48 respondents did not change their score between survey 1 and 2 including the control group.

22 respondents in the control group did not change their scores - the total group (100%).

26 respondents who were not in the control group also did not change their score (46%).

30 respondents did change their score who were not in the control group (54%).

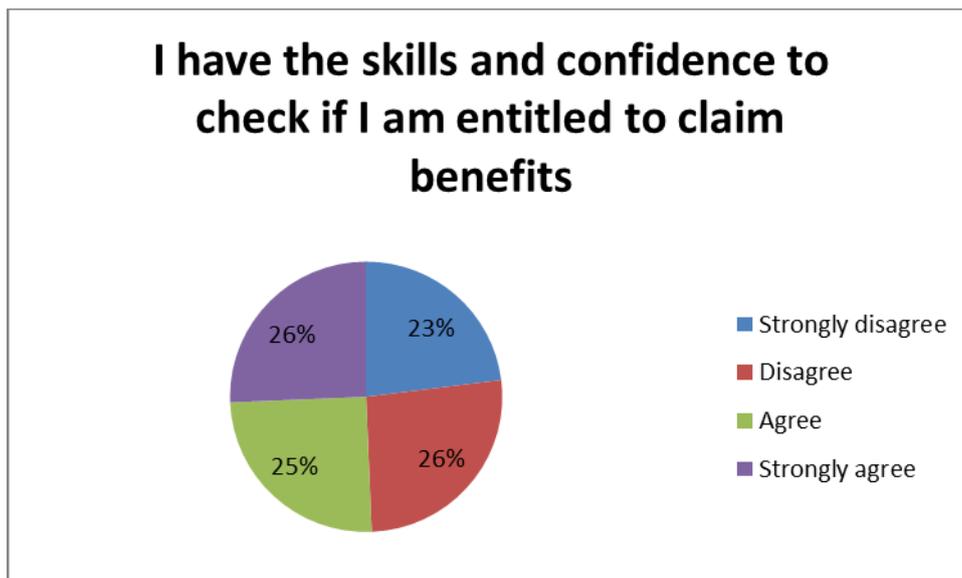
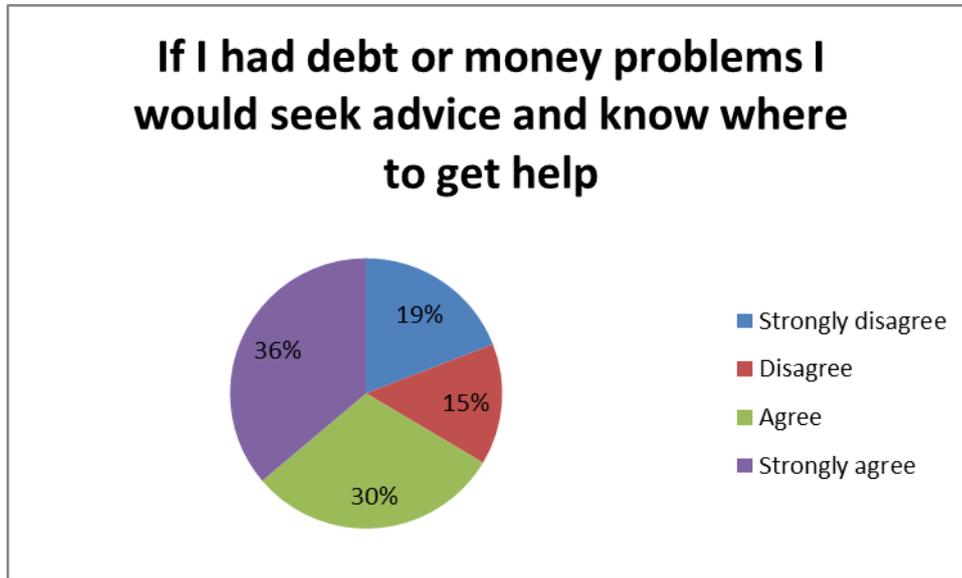
Therefore, slightly more respondents (4) who were not in the control group changed their score than did not.

In some individual question returns, the score went down after the intervention, whilst the majority that changed went up in score.

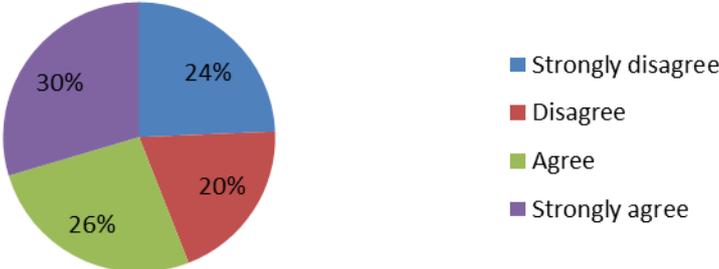
No changes were seen in the returns from the control group from baseline to follow up, but equally none was seen in 26 (46%) respondents who were not from the control group compared to 30 (54%) respondents who did change their score. Having said this, it does indicate that changes in knowledge and confidence may be slightly more likely to result from talking to, and getting advice from, a specialist. A larger sample and a completely separate control group would be required to test this further.

Annex 7: Survey charts

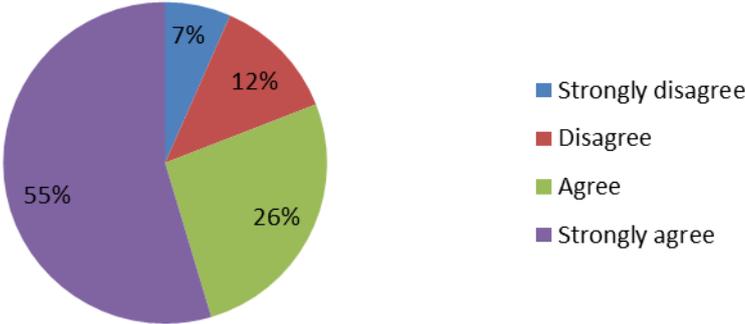
Baseline survey (n=152)



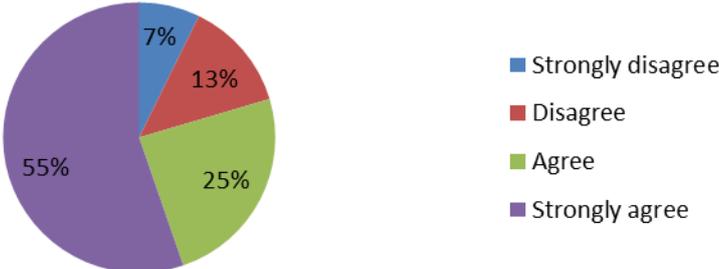
I talk openly and honestly to my friends and family about my money situation



I keep track of my spending and I feel in control of my money



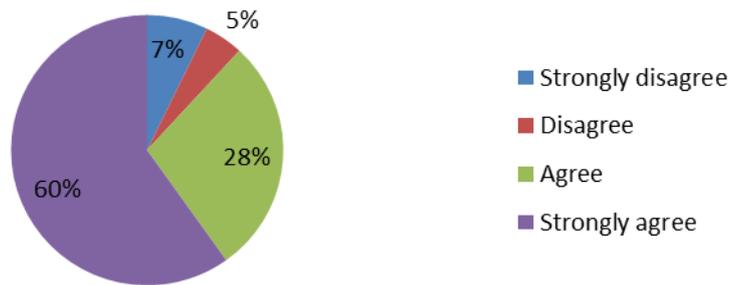
I plan ahead to make sure I have money to pay expected costs (such as utility bills)



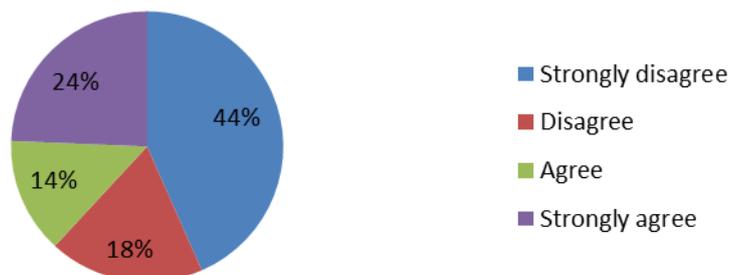
I plan ahead to make sure I have money to pay unexpected costs (such as car repairs or replacing household items)



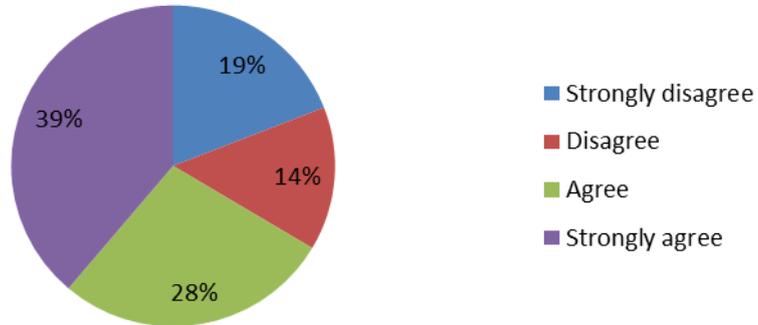
I know how to get copies of my bank statements and I can understand them



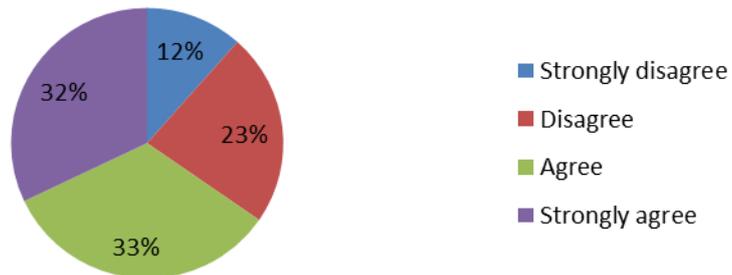
I am able to use the internet when I need information and advice about money or benefits



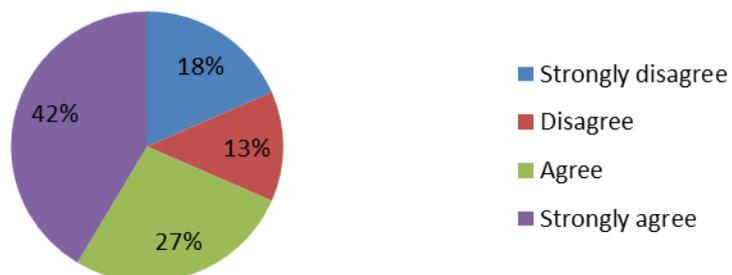
I know about 'scams' and how to avoid them



I talk openly and honestly to my friends and family about my money situation



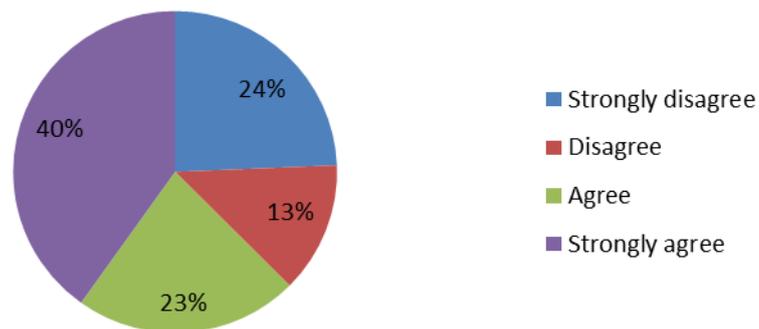
I understand my energy bills and how to use my gas and electricity so I don't waste money



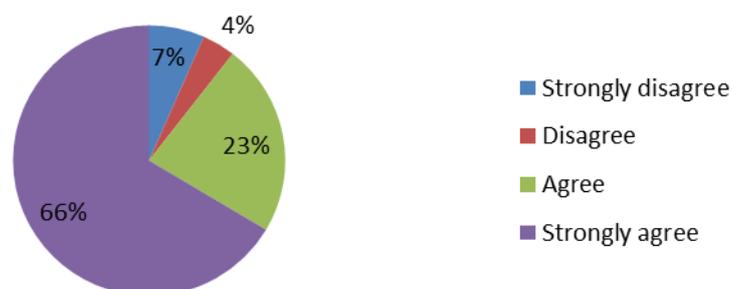
I am able to buy things that would help me to cope with my health condition (such as adaptations/aids or special dietary foods)



I don't often worry or feel stressed about my money situation

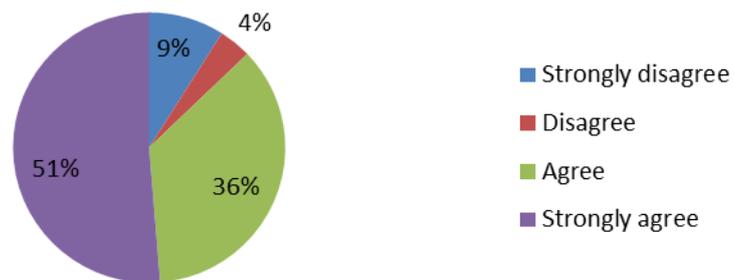


If I needed help with my money or benefit problems I would prefer to talk to a specialist advice worker

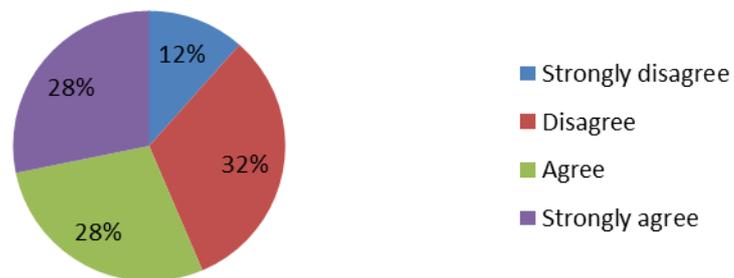


Survey 2 (n=78 including the control group)

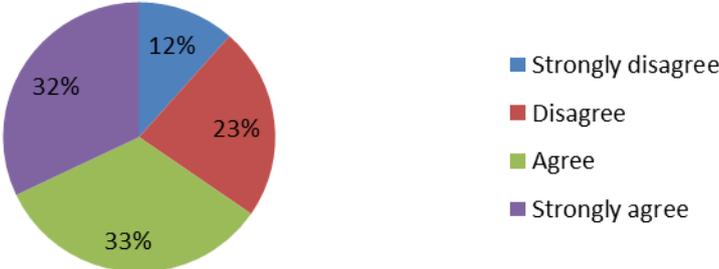
If I had debt or money problems I would seek advice and know where to get help



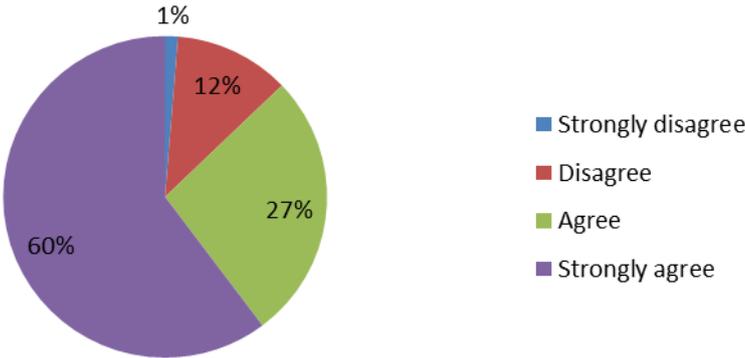
I have the skills and confidence to check if I am entitled to claim benefits



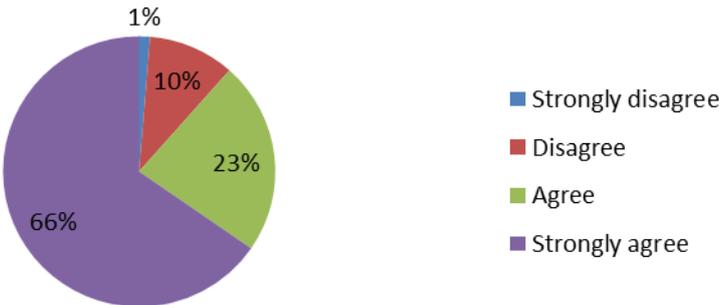
I talk openly and honestly to my friends and family about my money situation



I keep track of my spending and I feel in control of my money



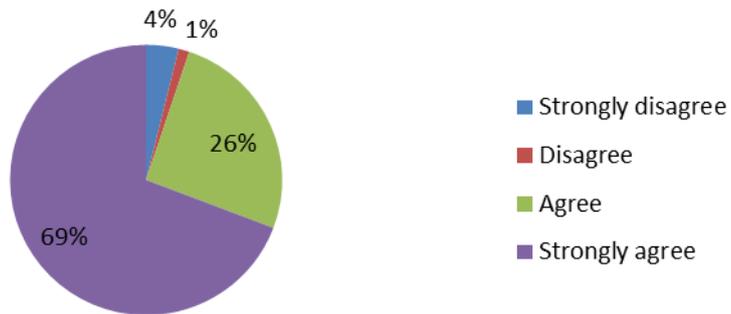
I plan ahead to make sure I have money to pay expected costs (such as utility bills)



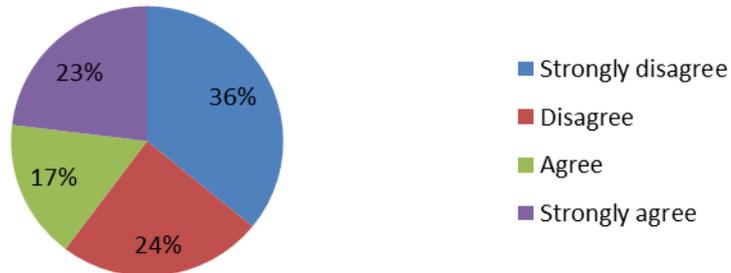
I plan ahead to make sure I have money to pay unexpected costs (such as car repairs or replacing household items)



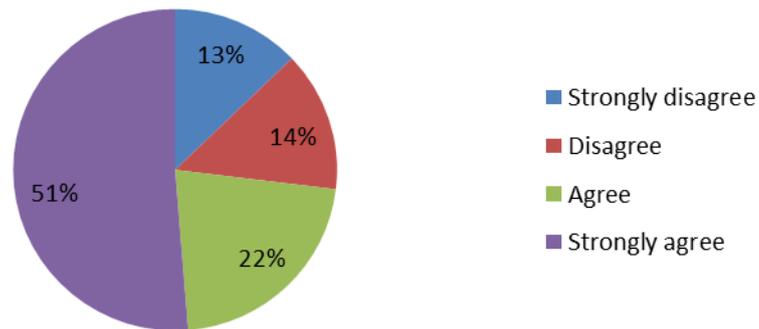
I know how to get copies of my bank statements and I can understand them



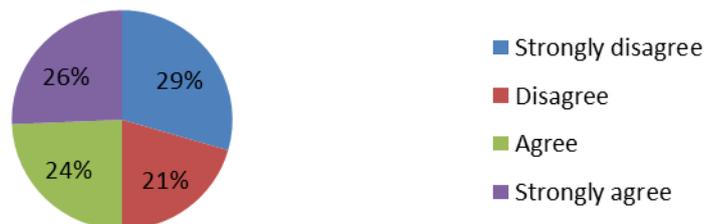
I am able to use the internet when I need information and advice about money or benefits



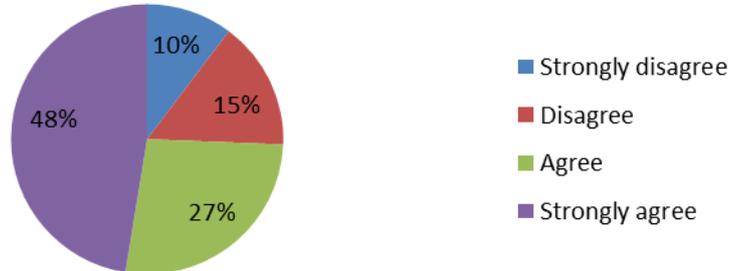
I know about 'scams' and how to avoid them



I know how to shop around and compare best deals for at least two of the following: Gas/Electricity, Mobile phone/broadband, Credit...



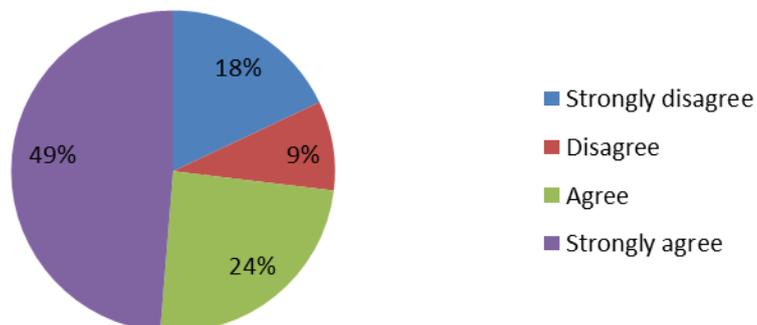
I understand my energy bills and how to use my gas and electricity so I don't waste money



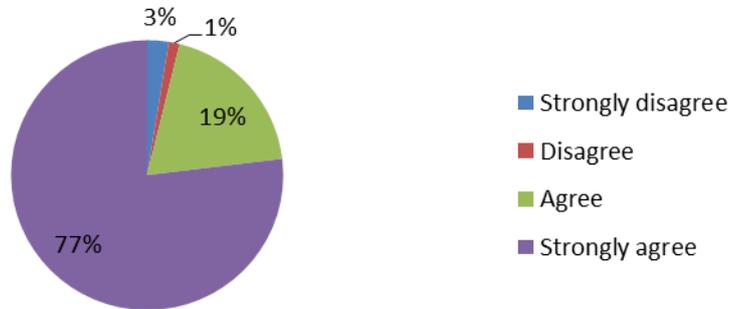
I am able to buy things that would help me to cope with my health condition (such as adaptations/aids or special dietary foods)



I don't often worry or feel stressed about my money situation



If I needed help with my money or benefit problems I would prefer to talk to a specialist advice worker



Annex 8: Case studies

Case study 1

Woman, age 62

Health issues: She has just been diagnosed with stage 5 renal failure and has not yet started dialysis. She has angina attacks, low energy, feels tired, has arthritis and poor mobility, and a bronchial tube blockage. The cold makes her chest worse and she gets angina attacks as a result.

Family situation: She lives with her two sons, one of whom has a sporadic income in a removal business. The other has bipolar disorder and needs a lot of support from the client.

Pre dialysis situation: She worked at a car manufacturer, but gave up work when she started angina attacks and chest infections.

Reason for contacting Auriga:

“I wasn’t sure if getting the right benefits at £102 per week. They were taking for £20 per week rent and council tax arrears. Left me with £84 per week. I was really struggling to live. My son does house removals you get a lot of dips and highs, there were getting to be a lot of dips at this time of year. There was very little left for food. When I tried on my own for PIP I didn’t get anything. When you get to the interview they don’t ask you any of the questions you had on the form. They refused me. (Cries). We were living on beans on toast. That doesn’t help my health condition, I need to be eating fruit and vegetables.”

Work with Auriga:

The hospital made a referral to Auriga when she reached stage 5 renal failure. They did a Financial Statement to check if she could make her repayments. The adviser at Auriga rescheduled her arrears and where they were not correctly applied they were written-off. She now has PIP and a basic bank account. She is able to keep the heating on overnight, so her chest pain is lessened. She receives Warm Home discount. She has a dryer from a grant scheme so she can get her washing dry and not leave it around the house causing damp air.

She is applying for Blue Badge so her brother can take her to hospital. She also has aids and adaptations for the house to reduce her dizziness when standing – including a stabilising bar for beside the bed and a seat for the bath. She has a seat so she can cook in the kitchen.

Stress/health:

“I feel a lot more relaxed with more money coming in. I can ring them any time. It’s a lot off my mind. I haven’t got the strength to get to the shops. All my money was going out on bills. Now I can order shopping online.”

Financial capability:

“I know what I’m doing. I pay most bills by direct debit. I use pre-payments for gas and electric meters so I can tell what I’m using. I’m more financially stable with PIP. If the boys have a low in their income, it’s not such a concern.”

Case study 2

Male, age 62

Time on dialysis: 4 years

Health issues: Kidney failure is the side effect of diabetes medication. He is on the waiting list for a replacement kidney. “I wasn’t aware I was diabetic until I got gangrene in my toe.”

Family situation: He lives with wife and 2 daughters - one is a doctor, other is a transport analyst, and he displays immense pride in them. His wife is a supply teacher and has no work during the holidays and then is on JSA.

Pre dialysis situation: He worked as an insurance underwriter for 23 years, from a laptop, travelling all around the country.

Reason for contacting Auriga: “I lived on savings for four years. Now the savings have run out. I didn’t want to claim. I hate claiming. I paid all the bills for 4 years. I didn’t take a penny from my daughters. But now it’s finished and the bills are still coming in.”

Work with Auriga:

“I owe Auriga everything. If she says she will drop you a line tomorrow it comes then.”
He has claimed PIP and a Blue Badge.

Stress/health:

“I don’t have anything to pay for my car, car insurance petrol. It will help with that at least. I get tired when I walk. A Blue Badge makes parking less of a pain. Parking at the hospital is so expensive.”

“I am just waiting for my kidney transplant. I will stop all these claims. I’ll go back to work because I am a qualified loss adjuster. I can work from home. The job is there. There’s plenty of work outside. If they give me a kidney today, tomorrow I will be back at work.”

Financial capability:

He was very aware of all the materials within the fact sheets from Auriga, and read them, and remembered chatting about them with Auriga. He felt he knew most of the information already, paid everything by direct debit, and did not want to change energy provider, but he did think about saving energy more now since reading the fact sheets.

“I know all about computers. I was one of the first to have a mobile phone in my car. I use a laptop for work. I understand all those scams, being from the insurance business.”

Case study 3

Male, age 54

Time on dialysis: 3 years

Health issues: He had diabetes and untreated high blood pressure. “Being a man I was told I had high BP, and I just ignored it. Hence I ended up with pneumonia and renal failure. I had serious blood poisoning. My foot was rotting and I was refusing to dialyse. I’d lost the plot really. I went into hospital and started pulling myself together.” He is now disabled as a result of his toes being amputated. “I keep falling out the shower. I laugh about it but my brother says you could break your arm, then you’d have that to deal with’.”

Family situation: He was divorced as a result of dialysis at home: “Home dialysis destroyed my relationship. It’s no good. You’re never away from it. [Partners name] couldn’t cope with it.” They sold the family home at a low price, and he became homeless. “My family and friends have helped me Big Time. I have people looking out for me.” A friend takes him to and from the renal unit in a taxi and stays with him until he is stable after each treatment.

Pre dialysis situation: He worked as a taxi driver.

Reason for contacting Auriga:

“My brother works in the NHS and he realised I still needed a lot of help. I had ended up in just the clothes I stood up in.”

Work with Auriga:

“Auriga helped me, explained to me. [Auriga worker] has been a font of information. She did it at my pace. On reflection that was very patient of her. She would say ‘this is available’ and I would say ‘I have to think about it’. She’d say ‘come back to me when you decide’. My brother would say ‘don’t be a plonker, get on with it’. I was reluctant to have benefits. But common sense made me think I don’t know if I can work again.”

He is now on a high rate of benefits including PIP. He has applied to get a bar for the shower to help his stability.

Stress/health:

“It’s all happened very quickly. It’s been a roller coaster. My son insisted I lived with him as I was still very unwell, so he could keep an eye on me...I believe I will survive on the money I’m getting. I know how to budget. I have always been able to budget.”

“I’m just starting to settle. I’ve got a very nice flat, which I’m decorating and furnishing. Then I shall be climbing the walls soon, I want to get out and you know, do something. I drive an automatic - I can still drive. My daughter lives down south, and I’ve driven there a couple of times. I’d like to start the taxi business again. ”

Case study 4

Woman, age 38

Time on dialysis: 10 years

Health issues: She had pre-eclampsia which led to kidney failure and loss of a baby. She has a bad knee which means she cannot climb stairs. She had a major operation on her arm to raise the vein to the surface to allow the dialysis line to be fitted. She had a failed kidney transplant and spent a year in hospital. She had a thyroid problem which is being treated.

Family situation: She lives with her sister who is her full time carer in a council property, with her 11 year old son. Her mum comes and goes and is not a permanent resident but was very supportive when she was diagnosed. Her husband was in Pakistan, and only came over 2 months ago. She is 7 weeks pregnant.

Pre dialysis situation: She worked in a clothes shop.

Reason for contacting Auriga:

“They [Auriga] sent out a letter saying they can help with so and so. They organised a home visit.”

Work with Auriga:

She was encouraged to get aids and adaptations from the local authority which she now has in place, carried out benefit checks, and are aiming to get carer support for her sister.

“They helped with my water scheme but I missed a payment...I have a memory problem. They are trying to get me onto it again. She asked if I get proper benefits and all that... I’m on ESA and disability. Child Benefit and Tax Credit.”

“I would work with them [Auriga] again. It’s helped me. I know she gives me better advice. Anything I can ask. When I ring the office the lady chats with me too.”

Stress/health:

“All my life was tuned around. My whole family too. Whenever we have a family gathering they have to work around me.”

Financial capability:

“I do get worried with bills. It’s so expensive. Groceries...TV licence, electric, water. £100/200 at a time-it’s a lot. I use a pre-payment meter. My sister helps me, reminds me. I do direct debit, but I have to pay bills myself. If you want to go out you have to cut from here and there.”

“I would like to have a little bit financial stability. My son is starting a new school, they want expensive things at secondary school. It’s hard to say no then. I need a better property with a new baby, it’s not suitable.”

Case study 5

Woman, age 39

Health issues: She has been having dialysis for a total of 12 year and also has had two failed kidney transplants. She is registered as blind. She has to buy extra clothing and additional apparatus for around the home due to reduced mobility, and inability to get to the bathroom, plus additional heating. She feels tired most of the time, and doing things around the house is very difficult. “I didn’t think it would be hard but it is hard. Especially when you wake up in the morning and you’re still tired. You recover and then you’re back again [in dialysis].”

Family situation: She lives with her 13 year old daughter, who also has kidney problems which are reasonably easily managed at the moment. She has a carer come in twice daily. Her husband left her when she became ill with a failed kidney transplant, and she kept her daughter after a custody battle.

Pre dialysis situation: She has never worked: “I’ve spent a lifetime in hospital.” Before receiving dialysis she was married and her partner was receiving carers allowance. She felt she was not being taken care of, and her husband went abroad every couple of months and she didn’t have money for basic things and had to rely on other family members. He wanted to take her DLA from her, but she did not allow this to happen.

Reason for contacting Auriga:

“I was desperate of additional financial support. The hospital staff made me aware of Auriga. Auriga staff helped me reduce the cost of heating and water bills.”

Work with Auriga:

Auriga helped her obtain a road ramp for easier street access and to secure grant funding for special glasses with a camera attached, which help with her sight problems and colour-blindness. Auriga also helped with PIP application and were present for the interview at her home.

“I don't feel scared or that [staff member] will judge me in any way. [Staff member] will give some advice and allow me to make my own decision...[staff member] say 'you think about it, how do you feel about it' which is nice...[staff member] aren't taking over...”

She runs issues with bills and tax credits past the Auriga team, and she feels Auriga have helped her manage her bills better.

Stress/health:

She feels less stressed about money and that tackling problems is now easier. She says she is able to afford a better diet which she thinks is great for young daughter who also has kidney problems.

Financial capability:

She doesn't do online banking but Auriga staff have made her aware of the risks. Her brother helps her manage her money and make sure bills are paid, but she reports that Auriga staff have helped her with reducing unnecessary costs.

She says she feels confident that things are under control but will still want continued support from Auriga. "I hope they can keep the company open...[staff member] have helped a lot of people and [they] deserve it. It would be really sad if they left."

Case study 6

Woman, age 50

Health issues:

She suffered kidney failure in 2010 and has had a failed kidney transplant. She has been coming for dialysis since 2014. She has severe back pain so is unable to go up and down stairs. She has extra food expenses including her special diet as she has a gluten allergy. She can't move her arm due the fistula. Additional heating is needed at home, and after dialysis feels "... very, very cold. The heating is always on."

Family situation:

She lives with her son, who bought the house for her to live in, plus her daughter and husband who is her carer, and gave up his job to do this. Her daughter and son both work. Her daughter helps her wash her hair and shower.

Pre dialysis situation:

She says she was a housewife, and brought up their children.

Reason for contacting Auriga:

Her DLA and her husband's carers allowance, as well as her council tax rebate were stopped at the same time. "Six or seven weeks we were struggling. They stopped Council Tax, everything. I don't have any money, but they stopped my husband as well. The stopped both of us. People genuinely need help, and they [DWP] are not giving it."

The unit staff made her aware of Auriga and how they would be able to help with benefits.

Work with Auriga:

Auriga staff prepared a Tribunal case which she believes they did very well. One staff member prepared then case and one represented them at Tribunal. The benefits were reinstated after the Tribunal several months later when she received a back payment.

Auriga also helped with rails around patients home and is applying for grants for various aids and adaptations.

“If she’s not here [staff member], we’re struggling.”

Stress/health:

She reports feeling less stressed now the benefits are reinstated, and managing her health better with the additional income and support.

Financial capability:

She now sets aside money for her special gluten free diet. She buys her personal things like soft clothes and shoes which help her manage her back condition.

Case study 7**Male, age 57****Health issues:**

He has been having dialysis for 4 years. He was diagnosed with extremely high blood pressure which “knocked my kidneys out”. He is not eligible for a kidney transplant due to high BMI. He is limited to only drinking 1 litre of water a day due to fluid build-up. He has to have a special diet to reduce his BMI and increase his calcium, which he is deficient in. He has a thyroid problem. He is very limited in his mobility due to a calcium deficiency.

Family situation:

He lives alone, but has grown up children and also a school age child living with his ex-partner. He pays for domestic help for additional help doing things around the house, due to mobility issues.

Pre dialysis situation:

He was working full time as a fork life driver before receiving dialysis but he wasn’t in good health. He now works as a doorman at weekends.

Reason for contacting Auriga:

“I was managing OK until all this PIP started. It was the toughest time of my life. I was already just about surviving...to see it all taken away. I just couldn’t believe it... I didn’t know whether to turn left or right. I would have gone homeless. I really think I would.”

“I’d reached the lowest point of my life. I spoke to that nurse here. She says well get in touch and we started talking from there.”

Work with Auriga:

Auriga staff have helped him secure rails around the house to help with mobility, a high chair in the kitchen for cooking, and a fridge-freezer, to help with his special diet.

He was in considerable debt, and received financial information from staff members which ultimately led patient to declaring bankruptcy. Auriga helped patient him reduce his water bill costs.

“[Without Auriga] I would have gone homeless because financially I wouldn’t have been able to survive. It was like angels sent from heaven.”

Stress/health:

He feels financially things are more positive and is grateful for all the help received. With his extra finances he can employ additional financial support, support around the home.

“I am on a special diet. Mainly fish, chicken stuff like that. It’s expensive and I can’t afford to eat like that all the time. I try and budget.”

Financial capability:

He has a token meter and was happy with this method of managing energy. He doesn’t do online banking and doesn’t have Wi-Fi.

He is paid weekly and divides money for essential expenses including his kids, food and transport.

He is good at budgeting and always has been, he knows what his income and outgoings are – he does it in his head, as he knows what his outgoing s are and what’s in the bank.

Case study 8

Male, in his early sixties

Health issues: He had been on home dialysis for nearly one year, having fought the diagnosis he had of renal failure.

Family situation: He lives with partner, who had been supporting him with home dialysis. They live in a very remote rural location. His sister died relatively recently from kidney failure, as they both had a hereditary disease causing kidney problems.

Pre dialysis situation: He works in the same job he always has had on the land. He 'retired' two years ago, but does part time work now.

Reason for contacting Auriga:

He saw a sign for Auriga in the Smethwick Unit where the home dialysis is organised and supported from. He wanted a Blue Badge for his car to help him get around within his rural location, and get to the support unit for home dialysis.

Work with Auriga:

Auriga went through "lots of things" including energy costs with but he didn't feel that was relevant at the time but would be useful in the future. "A few things she said might come in later life, and I know about it now."

Auriga helped him gain Attendance Allowance for someone to come and sit with him while conducting his home dialysis. "I'm not thick but I had never heard of Attendance Allowance. I never knew it existed. She (Auriga) got it for me."

Home dialysis needs to be supervised throughout the procedure in case of an emergency, and his wife had been doing this for him, although this was quite unsafe. "When my wife was sitting with me I 'crashed' and it scared her half to death. Now I have someone sit with me which is bloody brilliant." He also gained assistance for home dialysis to set up and clean the dialysis machine after his treatment which takes several hours.

Stress/health:

"At the moment I'm cooking on gas, I feel quite chirpy, but things can go either way can't they. My sister died while back from kidney failure, so you don't always know what coming in future."

Financial capability:

"I've never had nothing given to me in my whole life, so you don't expect anything. So when I got Attendance Allowance and my Blue Badge I'm over the moon."