



# An Evaluation of Age UK's Person Centred Discharge Pathfinder Programme

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# An Evaluation of Age UK's Person Centred Discharge Pathfinder Programme

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# Key Observations and Learning

The findings presented in this report point to the Person Centred Discharge (PCD) Pathfinder Programme achieving the following measures of success:

- **The involvement of Age UK Personal Independence Coordinators (PICs) facilitates better communication e.g. between GPs and hospital.**
- **PICs are able to help make the discharge process take account of the older person's preferences and situation and make older people feel more comfortable about being discharged.**
- **PICs are able to improve the wellbeing of older people once they are out of hospital in a sustainable way.**

This evaluation also highlights some of the challenges for the PCD Pathfinder Programme and provides observations and learning which may be beneficial for future Programmes.

## Setting up the Programme

- The experience of both PCD Pathfinder areas demonstrates the importance of finding a key person or advocate who can authorise decisions and make things happen.
- Being able to evidence how the Pathfinder could make a difference in solving some of the problems facing Hospital Trusts in a way which was meaningful and understandable to the partners involved was beneficial with project 'buy-in'. Being recognised as part of a GP surgery was also important.
- Information governance and getting authorisations for data sharing and linking were considerable challenges which caused both Pathfinders significant delay. These delays often resulted in GP partners losing enthusiasm for the project and a loss of project momentum.
- For such Programmes to proceed therefore, it was vital to have someone who understood information governance and risk stratification and could link to other business and service opportunities.
- Factors identified which helped to facilitate data sharing arrangements were:
  - Awareness of the legal framework for sharing data and legal precedents around sharing patients' medical records if data is to be used for delivering improved clinical care.
  - Checking the compatibility of data systems.
  - Ensuring Age UK staff have honorary contracts with the GP practice so that they can use the data analysis, providing appropriate safeguards are in place.

- Understanding the technical requirements of the tools that are being used.
- Making sure issues around consent are understood and handled sensitively. Developing simple consent and privacy processes and taking a sensitive approach to gaining consent is of particular importance when working with people who are vulnerable.

## Risk Stratification Tool (RST)

- Whilst the tool was able to identify a broad group of patients who might be at risk of being a delayed discharge, the PCD Programme didn't define what the risk was or the appropriate risk level for intervention.
- More thought was needed around how the tool and the PCD model could be best embedded into Multi-Disciplinary Teams (MDTs).
- However, the RST offered tangible benefits for the GP surgery using the tool by enabling the surgery to interrogate its patient population which was helpful in managing and planning demand.
- The RST also enhanced opportunities to develop new ways of working by helping inform the development of services. For example, by utilising the tool the surgery was able to reduce prescribing costs and spend in the practice by identifying patients at risk of poly-pharmacy and reviewing these cases and improving the quality of prescribing.

## Implementation

- Once operational, having the same people regularly attending the hospital helped hospital staff recognise the Age UK PIC team and was beneficial for developing relationships. The importance of PICs being a visible presence on hospital wards and having a proper base at hospital was stressed as this helped provide continuity and build relationships.
- Getting to know teams such as Onward Care, Rapid Response and Rehabilitation was particularly useful as they know who is being discharged and understand the complexity of discharge. Such teams are often willing to work with a project like the PCD Pathfinder as they see directly the difference the PICs make.
- The significance of building relationships and gaining trust cannot be over emphasised and it was apparent that a great deal of the PICs' time was spent strengthening relationships across a range of different agencies and with working alongside NHS staff.
- The PCD Pathfinder Programme was a flexible and responsive service which was valued by other healthcare professionals. Despite the challenges that exist within the health and social care system which can lead to delayed discharge, other healthcare professionals felt PICs added value by being able to respond flexibly and work between services.
- PICs provided a means of sorting out the "*little things*" that can often delay discharge or prevent a patient from going home to a safe environment. In particular, PICs solved problems that could hold up discharge and were often outside the remit of other hospital staff. The service also provided assurance for hospital staff that there is back up and continuity for patients at home after discharge.
- Our findings suggest that organisations like Age UK and the voluntary sector can make a positive contribution by providing support to older people in an acute setting, and especially supporting hospital discharge.

## The Role of the Personal Independence Coordinator (PIC)

- The role of the PIC itself was seen as a very fluid sophisticated role which demanded a variety of skills and knowledge, rather like an enhanced healthcare role or an "*old fashioned OT*" and was aligned to a community navigator role. The evaluation particularly highlights the demands

of the role of the PIC, with the ability to navigate and negotiate a way through the health care system a vital skill crucial to the successful implementation of the project.

- PICs were able to do the “*joining up bit*” to ensure the care and support a patient was receiving after discharge was appropriate. The PICs benefited other services in various ways, for example, being able to identify what agencies were involved in a patient's care, highlighting any duplication, filling in gaps in provision and notifying agencies if action was needed.
- Many of the small things that PICs did for the people they were working with usually led onto much bigger things, often having beneficial impacts on the daily lives, social isolation and wellbeing of the people PICs worked with. The variety of support, options, choices and services offered and facilitated by PICs helped older people to try out opportunities and build solutions that were more likely to work for them in the longer term. These longer-term solutions were not something other healthcare professionals typically had the time or knowledge to facilitate.
- PICs also spent much of their time supporting people to (re)connect with their communities. PICs' local contacts, networks and knowledge of what was available in the local area and community was of vital importance. It takes time to acquire such knowledge as there is often a wide range of volunteer local led activities out there. If there are no up to date directories or databases of local support PICs may need to spend some time getting out and about building local contacts to develop such knowledge.
- Ensuring the individual was aware of the amount and type of contact they would receive and that support or information to access support was available to the individual when the PIC moved away or signposted onto other agencies was essential.

# Introduction

## 1.1. Introduction

This report presents the findings from an evaluation of Age UK's Person Centred Discharge (PCD) Pathfinder commissioned by Age UK. The evaluation was carried out between June 2017 and March 2019 by the Centre for Regional Economic and Social Research (CRESR) at Sheffield Hallam University and involved two Pathfinder areas, Cornwall and North Tyneside.

## 1.2. Background

Over recent years Age UK has developed a voluntary sector led transformation programme focused on improving the lives of older people.

Working with a target group of older people with long term conditions and a history of avoidable and unplanned emergency hospital admissions, the aim has been to integrate the voluntary sector into the provision of health and social care services and combine both medical and non-medical support. This Personalised Integrated Care model involves Age UK working alongside local Age UKs in local partnerships. These partnerships bring a senior leadership group together in a shared health and social care system to undertake transformational change to the way care is delivered for older people. The programme is primarily designed to enable older people to receive a broader service that meets their wider goals, needs and aspirations so they can live well and independently. The model also draws on and develops social capital within communities by using volunteers and re-engages older people with their communities to create sustainable social networks to reduce loneliness and encourage greater promotion of self-care.

However, it is recognised that some people will inevitably be admitted to hospital despite these best efforts and there is a need to ensure that the older person has a safe and effective discharge from hospital to the most appropriate place, whether that is their home or elsewhere. As such, Age UK worked with local Age UKs, acute hospital trusts, clinicians and external consultants to develop an Age UK approach to this issue. This consultation culminated in the development of the PCD Pathfinder Programme to test a new way of working in a hospital setting in two different sites, Cornwall and North Tyneside.

## 1.3. The Person Centred Discharge Pathfinder

The Age UK Person Centred Discharge (PCD) Pathfinder developed in response to the rising demands of an ageing population which a disjointed health and social care system is increasingly regarded as failing to cope with. Too many older people experience multiple chronic health conditions and are not getting the person centred,

coordinated care and support they need to live full and independent lives at home. A lack of appropriate support often means that older people experience unnecessary stays in hospital and end up going in and out of hospital because there isn't an adequate and sustainable plan of support to keep them fit and well at home.

Delays in discharge are also increasingly common. It is estimated that such delays cost the NHS £820 million a year, with some patients being sent home under inappropriate and unsafe circumstances (NAO, 2016)<sup>1</sup>. In particular, delayed transfers of care where a patient is ready and safe to leave hospital care, but is unable to do so, have increased dramatically. Figures show that in 2016/17 there were 2.3 million delayed transfer days in England and that the average number of delayed days for 2016/17 was 25% higher than the year before. Most commentators attribute this rise to the increasing pressures on social care related to such things as patients having to wait for a suitable home care package to be arranged or for a place in a residential care home to be found. Although most delayed days are attributable to the NHS, delays attributable to local authority social care have risen by 85% over the past two years (House of Commons Library, 2017 no. 7415)<sup>2</sup>.

Unnecessary hospital stays<sup>3</sup> and longer periods in hospital have a particularly detrimental effect on older people's health, mobility and wellbeing. NICE (NG27) have issued guidelines on *Transition between inpatient hospital settings and community or care home settings for adults with social care needs* which aim to improve people's experience of hospital admission and discharge by enhancing coordination of health and social care services.

The PCD Pathfinder was set up to address the following issues:

- **Poor communication between the GP practice and the hospital**, meaning that important information about an older person's health does not inform their hospital care.
- Older people's **personal or practical concerns when they are in hospital can be overlooked** as the focus is on addressing their medical needs.
- Older people and their family/carers are often **not kept involved in decisions about their care** while in hospital.
- Current 'Home from Hospital' services are **not targeted at those who are most at risk** of extended length of hospital stay and have become too much 'part of the system' rather than being able to advocate on behalf of the older person.
- Older people often **stay in hospital longer than necessary**, which can be detrimental to their health and wellbeing.
- A hospital admission can result in older people being **prematurely admitted to a care home** against their wishes.
- There may be **underlying issues that could lead to an older person being readmitted to hospital that could be addressed** with support in the community.

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<sup>1</sup> National Audit Office (2016) *Discharging older patients from hospital* <https://www.shutterstock.com/image-photo/caregiver-helps-older-woman-groceries-636532136>

<sup>2</sup> House of Commons Library, 2017 Briefing Paper no.7415, *Delayed transfers of care in the NHS* <http://researchbriefings.files.parliament.uk/documents/CBP-7415/CBP-7415.pdf>

<sup>3</sup> <https://www.ageuk.org.uk/latest-press/articles/2017/october/four-million-hospital-bed-days-lost-since-2011-due-to-problems-securing-social-care/>

The PCD Pathfinder seeks to respond to these challenges by working to:

- Facilitate the flow of necessary information between the hospital and GP practice.
- Have a Guided Conversation with the older person to **understand and address any concerns they may have while in hospital.**
- **Act as an advocate for the older person** to ensure their voice is heard and they are **informed and involved in decisions about their care.**
- Work with the different parts of the health and care system to enable the older person to be **discharged from hospital as soon as they are medically fit, and to their own home** if that is their preference.
- Have a Guided Conversation with the older person after discharge in order to **improve their ongoing wellbeing** by supporting them to manage their conditions, achieve their goals and integrate with their community.

The PCD Pathfinder also sits within a broader context of health and social care integration and the development of new models of care including social prescribing which aim to deliver more personalised care and support, reduce hospital admissions, improve patient outcomes, reduce cost pressures on the NHS and deliver savings through better efficiency and value for money. The ambition is that by 2021 every part of the country should be an integrated care system (see NHS Long Term Plan)<sup>4</sup>.

The PCD Pathfinders in North Tyneside and Cornwall both built on several years of joint working with Age UK and the experience of other programmes including Changing Lives and Living Well Programmes. The Living Well Programme led to the development of locality teams, multi-disciplinary meetings involving the voluntary sector and community social prescribers, or navigators and has been held up as nationally acclaimed programme, winning a Health Service Journal Award and gaining national Pioneer status. The success of such programmes supports the growing acknowledgement of the valuable role the voluntary sector can play in contributing to patient care, through multi-disciplinary working, supporting people in their communities and reducing associated healthcare costs.

#### 1.4. The Person Centred Discharge Model of Delivery

Essentially, the aim of the PCD Pathfinder was to support patients (from identified GP surgeries) while in hospital with the transition from hospital back home and to provide some time limited support (around 8 weeks) at home afterwards.

There were two models of delivery. Both models used a predictive risk stratification tool within a primary care setting to identify older people at high risk of extended length of stay and admission to a care home.

**Approach 1** - Risk stratification happens within primary care across a whole population and so identifies older people hopefully before an admission to hospital. The process is similar to the Integrated Care Programme but with an extension whereby there is added resource and infrastructure developed with the acute trust to allow the Personal Independence Coordinator (PIC) worker to “reach in” to the hospital and support effective discharge back into the community.

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<sup>4</sup> <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/01/nhs-long-term-plan-june-2019.pdf>

**Approach 2** - Risk stratification happens when a person enters hospital either through a planned or unplanned admission. The hospital notifies the GP that one of the older people on their patient list has been admitted and the GP subsequently runs the risk analysis. If the person is flagged as being high risk at this stage, the GP alerts the community based Multi-Disciplinary Team (MDT) including the PIC to kick-start active discharge management, “reaching in” to the hospital to support the person to return back to the community/care home where they came from.

Following an application process Cornwall (Approach 2) and North Tyneside (Approach 1) were chosen to take forward the Pathfinder. Both these areas have previous experience of delivering the wider integrated care model. It was hoped that each area would work with 100 people and that the Pathfinders would run for a period of 12 months. (In all, the Cornwall Pathfinder supported 151 individuals over 18 months).

A risk tool was funded by Age UK and developed in partnership with an IT provider, DOCOBO, to support the identification of older people at risk of extended length of hospital stay. The tool which linked data across a variety of sources was used at primary care level and was vital to the development of the programme.

## **1.5. Report Structure**

The rest of the report is structured as follows:

- Chapter 2: The Evaluation Overview;
- Chapter 3: Process and Implementation;
- Chapter 4: Benefits and Impacts;
- Chapter 5: Learning and Conclusion;
- Appendix 1: Case Studies.

# The Evaluation Overview

## 2.1. The Aim of the Person Centred Discharge Pathfinder

The PCD Pathfinder set out to achieve four main outcomes:

- Improved quality of life for older people.
- Improved experience of health and social care for older people and staff.
- Reduced activity and cost of care and support.
- The service model is viable and can be delivered by Age UK brand partners.

Originally the focus of the evaluation was to concentrate on the first two outcomes and answer the following questions:

### *Improved quality of life for older people*

- Does the service support older people to improve their quality of life?
- Does the service enable older people to achieve their goals?
- Does the service support older people to express their wishes and support their discharge to their identified preferred place?

### *Improved experience of health and social care for older people and staff*

- Does the service improve older people's experience of hospital discharge?
- Does the service improve the carers' experience of hospital discharge?
- Do wider health and social care staff value Age UK's involvement and feel it contributes towards supporting older people?
- Do health and social care staff feel the service supports delivery of their role?
- Do health and social care staff feel the risk stratification tool supports the identification of people most at risk of extended length of stay?
- Is the Age UK worker a fully integrated member of the primary care Multi-Disciplinary Team (MDT)?

It was anticipated that the evaluation would help to:

- Provide useful evidence on the impact of the service, including experience of using/delivering the service.
- Highlight what worked and areas for improvement in each site.

- Highlight what worked well and areas for improvement across the Programme as a whole.
- Provide suggestions and ideas of other issues identified in the evaluation.

However, given the difficulties and delays encountered by the Pathfinder projects, the subsequent amendments to the evaluation and its limitations which are discussed below, it was not possible to answer all these questions.

## 2.2. Measures of Success

As alluded earlier there were a number of issues or challenges that the PCD Pathfinder Programme was attempting to respond to and a number of **measures of success** were developed for the programme. These were:

- Does involvement of Age UK staff **facilitate better communication and coordination** around hospital admissions between GP practices and hospital?
- Can PICs **improve older people's experience** of hospital and make them feel **more involved in decisions about their care**?
- Are PICs able to **influence how quickly someone is discharged from hospital and where they are discharged to** – reducing extended length of stay (LOS) and premature care home admission?
- Can PICs help make the discharge process reflect the older person's preferences and situation? Can they make older people **feel more comfortable about being discharged**?
- Are PICs able to **improve the wellbeing of older people** once they are out of hospital in a sustainable way?
- Does the involvement of the PIC make it **less likely that people will be readmitted into hospital** within the first 2 days/ first 30 days?

As outlined in Chapter 4 of the report, the evaluation provides some evidence around a number of these measures.

## 2.3. The Evaluation Approach

The evaluation of the PCD Pathfinder was a small-scale qualitative evaluation which was carried out in stages including scoping, stakeholder interviews, beneficiary case studies and reporting.

### *Scoping*

The scoping phase involved:

- Discussions with Age UK about the rationale, scope and outcomes for the PCD Pathfinders and their requirements in terms of evaluation evidence.
- Discussions with pilot sites in relation to local contexts and outcomes, and possibilities and limitations for local data collection.

### *Stakeholder Interviews*

Initial interviews were undertaken with both Pathfinder areas to gather evidence on local context and setting up issues during the scoping phase, and in Cornwall on the early aspects of implementation. Interviews were also conducted during the Pathfinder project in Cornwall and at the end of the project. These interviews were

concerned with ongoing implementation issues and the impact of the Pathfinder in improving the quality of life of older people and improving their experiences of health and social care. Final interviews in Cornwall also drew out learning from the Pathfinder and reflections on the approach adopted. Light touch updates and reflections on progress were conducted with North Tyneside.

Both face to face and telephone interviews were employed during the evaluation. Interviews were conducted on a face to face basis during visits to the Pathfinder sites and over the telephone at other times. Interviews were carried out with stakeholders including Age UK and partnership organisations.

### ***Beneficiary Case Studies***

This element of the evaluation included a qualitative longitudinal cohort study with a group of five people going through the hospital discharge process. Working with the Cornwall Pathfinder, case studies were conducted over a period of six months and involved a series of in-depth interviews with clients and with a relevant stakeholder involved in their care e.g. a family member or care giver or the PIC. One participant was unable to continue in the study for the whole six month period so data is included up until the time they left the study. Case studies were designed to capture the experience of the PCD project, the involvement of the PIC and how the service contributed to client need and outcomes e.g. quality of life.

### ***Reporting***

A short interim report documenting emerging themes, findings and lessons was produced for Age UK and presented at a Learning Event for the PCD Pathfinder Programme in April 2018.

This final report updates and expands on the interim report.

## **2.4. The Evaluation Timescale**

Originally the evaluation was due to be carried out between January and November 2017. However, challenges in setting up the PCD projects affected progress in both areas to varying degrees and resulted in changes to the evaluation plan and timescale.

In Cornwall, the evaluation was mainly carried out between June and December 2017, before the Risk Stratification Tool (RST) was in place. The project was scheduled to finish in March 2018 but was eventually extended till the end of September 2018, operating for a number of months with the stratification tool. In order to capture what the experience was like with and without the risk tool a small number of interviews were undertaken at the end of 2018 and in early 2019. In North Tyneside however, a decision was taken not to start the project until the stratification tool became operational. A series of delays and setbacks were experienced which postponed the start of the evaluation in this area. Unfortunately, due to reasons beyond the scope of the PCD Pathfinder Programme the project did not go ahead as planned. Although evaluative work did not proceed in North Tyneside as expected, Age UK North Tyneside was supportive of the evaluation. Some early interviews and ongoing updates during the set-up process were undertaken and our evaluation report is informed by learning from the North Tyneside experience as appropriate.

## **2.5. Limitations to the Evaluation**

As the evaluation did not go ahead as planned there are limitations to it which should be taken into account when reading this report. The report is largely based on one Pathfinder area so it has not been possible to compare the different models of delivery to identify what worked well in each site and where improvements could be made. Less evidence on the benefits and impacts for patients was gathered during the evaluation. We had planned to carry out ten detailed case studies with beneficiaries across both sites to assess whether the PCD Pathfinder improved the quality of life of older people and their experience of health and social care. However, as only one site went ahead with the project only five detailed case studies were undertaken. Delays in getting governance, data sharing and IT issues sorted, plus the uncertainties as to whether funding would continue beyond the first year of the Cornwall project, also meant that much of the fieldwork was undertaken before the RST was implemented and the Veor GP Surgery got involved.

Given these limitations, the results presented in the report are indicative rather than authoritative and should be treated with some caution.

# Process and Implementation

## 3.1. Setting up the Programme

Evidence gathered for the evaluation highlights the considerable time, effort and commitment it takes to develop and set up a Programme like the PCD Pathfinder. The early stages of preparation needed (to set up such a project) within the context of a hospital setting were extremely challenging and time consuming. Finding the right individuals and establishing the necessary relationships to support the project was difficult. There was also a sense that third sector organisations often had to work harder to prove their worth before being taken seriously by the health sector and NHS, despite previous successes.

*Every time we've had a service running in conjunction with health, we've always had to prove ourselves before they would take us seriously, and that's including meeting individuals, whatever role they are in the NHS. (Local Age UK).*

Pre-existing trusted relationships, knowing the right person who could authorise decisions to make things happen was a key factor in getting the Programme up and running and its overall success.

*Yeah, it's about knowing the title or job description of the person that you need to get alongside. I'm not naïve to think it's just like that, I've spent time building those relationships in the past so hopefully I'm trusted and when I say I'm doing something people recognise that I am doing it. (GP).*

In order to get buy-in it was essential to demonstrate in a meaningful and understandable way how the PCD Pathfinder could help solve some of the problems facing Hospital Trusts.

*...it's usually linking people up and translating the language into what they understand. Your problem is this programme helps you deal with that, that sounds interesting, ok I'll support that, but you go in saying 'I want to do this, this and this' and people go 'oh I don't see how it's going to help me' understand what their problem is and say 'this is how it will help you'. (GP).*

In West Cornwall it was perhaps easier to embed the PCD project because of these established working relationships. The legacy of the Living Well Programme meant that one of the PIC workers was already a trusted member of the MDT based at a GP surgery and there was greater awareness of the PIC role and its value.

*I knew that surgery anyway prior to this role, but for me it's being valued, cos you're not medical it's quite difficult to hold your own sometimes in those meetings but over time when people see what you've done, they value you and that's really positive. (PIC).*

Being attached to a GP surgery also helped hospital staff members take the project more seriously.

*...when you say you're part of the surgery they prick their ears up a bit. (PIC).*

In another part of Cornwall, the situation was different and without existing relationships or experience of MDT working it was more difficult to get 'buy-in' from GPs.

*For X it's much harder, you've got a much bigger site for the GPs, a great many more GPs attached, two surgeries under one health park, it's an enormous space with in the region of 10 GPs per practice, that's been much harder and they haven't experienced working in the Living Well way in the same way so they don't have the MDT meetings in the same way. (PIC).*

### **3.2. IT, data linking, sharing and governance**

The largest challenge with regard to the implementation of the PCD Pathfinder was sorting the data process and resolving issues around IT, information governance and data sharing and linking. Early on the PCD Pathfinder was beset with problems and delays which caused a great deal of frustration and impacted on project momentum. In both Cornwall and North Tyneside this led to GPs and practice managers losing enthusiasm for the Programme and made it more difficult to get further buy-in from other GP surgeries. In North Tyneside for example, one surgery the Pathfinder had been working with decided to pull out of the Pathfinder due to difficulties with extracting the data and the length of time it had taken to get to that stage.

*They [GPs] have been waiting for something to happen and are getting frustrated with delay and losing some enthusiasm for the project as a result. (PIC).*

*We have no idea, the last promise we had was by the end of June and that's been and gone. And the GPs are very frustrated that they've signed for something, so that's impacting on our relationship which is worrying for the organisation cos we don't want to lose that good relationship that we've had in the past cos of something that ultimately isn't our fault. (Local Age UK).*

*We have been regularly popping into the surgeries and keeping contact with them but it's hard when we don't have anything concrete because of the delays with DOCOBO. (Local Age UK).*

Issues related to getting authorisations for sharing data arrangements, the compatibility of different systems and problems with uploading data (particularly secondary data). As a result, the PCD Pathfinder Programme struggled to get the RST in place in both Pathfinder areas. Even with previous experience of data sharing through the Living Well Programme, resolving such issues took time and was extremely difficult due to the levels of complexity of data sharing across systems.

The experience of both Pathfinders shows that without key advocates who have the authority to drive things through within both GP and Hospital Trust settings, data sharing can become an issue that will stall programmes like this.

*The thing that took the time was getting the right signatures on the bits of paper that said we were allowed to have it [the data]. (GP).*

*..the problem we've got is we need this data, you agree as an organisation that I'm legally entitled to get the data, I'm just having problems with someone within your information team that basically is going 'I'm not certain I'm allowed to do*

*this so I'm going to drag my feet and basically not allow it to go', so [name] sends a nice email copying me in saying to this person this is the situation, this will be released by Monday otherwise I'll be escalating it to the chief exec, and guess what, it happened. (GP).*

Other factors which helped facilitate data sharing arrangements included:

- Awareness of the legal framework for sharing data and legal precedents around sharing patients' medical records if data is to be used for delivering improved clinical care.
- Checking that data systems are compatible.
- Ensuring Age UK staff have honorary contracts with the GP practice so that they can use the data analysis, providing appropriate safeguards are in place.
- Understanding the technical requirements of the tools that are being used.
- Making sure issues around consent are understood and handled sensitively.

### **3.3. Implementation in a hospital setting**

Once operational it took time to launch the PCD Pathfinder project on the ground in a hospital setting. Building the necessary relationships with staff working on wards in a large hospital was particularly challenging because initially it was difficult to identify the appropriate staff, see them regularly and build rapport. For the PICs having to explain who you are and what you are doing numerous times was often tiresome and time consuming.

*It's identifying the people and also getting a rapport with the staff cos they're shift workers and it's a big hospital, you never see the same nurse twice so you're constantly trying to explain your role again to them. (PIC).*

The importance of being a visible presence on hospital wards and having a proper base at hospital was stressed as this helped to provide continuity and build relationships.

*It needs to be based in one ward or somewhere cos it's that continuity of personnel, seeing the same people, building relationships. (PIC).*

The experience of the PICs suggests that even with such a base it can take some months to become recognised and feel part of a team. Once PICs were established, identifying and working with key people like Discharge or Ward Clerks and Onward Care teams was vital for the successful operation of the service.

*Some of the best people are there Monday to Friday like the discharge clerk cos they know everybody who's coming out and going in, so I found that was quite valuable to make contact with them. (PIC).*

*Once you get a few, you meet an OT who's really keen and build on that relationship and she'll pass it on to the other OTs and members of staff. (PIC).*

A challenge for PICs when going into the hospital was trying to identify patients from a particular surgery.

*On the first part of the project before we had the tool what we did was we went to ward rounds to try and identify people, but again we stopped that cos you get up on a ward with 40 or 50 people and you'd spend time on it and none of the people, by the time you'd walked round on a ward round with the specialists and*

*things, none of them were from the surgery we were operating at and we had to keep saying no which was a little embarrassing to say the least. (PIC).*

Only working with one surgery restricted the pool of patients available and meant there were lots of suitable patients that couldn't be helped. This could be difficult to explain to hospital staff when they were faced with a number of people on the ward who could potentially benefit from the type of support being offered by the PCD project.

*One of the problems with it as well with going into the hospital and just trying to identify people from one surgery when there's a whole hospital there, care coordinators, the onward care social workers, I think found it a bit odd that they'd got all these people that we could have helped, but we couldn't help cos they weren't from the surgery, and that was sometimes a bit difficult to explain. (PIC).*

Working in hospital also required particular skills and was not something everyone was suited to.

*... to work in an acute hospital setting is not something that everybody is able to do and until you're in that situation you're not sure that you can cope with the sights, the smells, the speed and the staff who are busy, not being rude, but it's a very difficult thing and I think that's something that we weren't aware of that would be an issue. (Local Age UK).*

In addition, working from an acute setting out into the community was viewed as more challenging by those delivering the project compared to the previous experience of the Living Well Programme. It was felt that being based in the hospital probably required more resource and demanded more time management (this may have partly been due to not having the RST in place at the time, and the additional time it was taking to go through information and identify patients).

*We're working from the acute setting out into the community which is more of a challenge. (PIC).*

*It is a very big job cos you've got the hospital side and you've got the primary care side. (PIC).*

*Personally, I think in terms of manpower and time management being based in the GP surgery would be better. (PIC).*

There were questions about the PCD model employed in Cornwall and whether being based in hospital was as effective compared to operating in the community and identifying those at risk earlier i.e. before they were admitted to hospital.

*Everybody can see the longer term benefits of having something like this, whether it's this model or other models where you have them working to prevent the hospital admission in the first place, I think that still would be an interesting thing and I think perhaps we're thinking the other model may be a better model, more preventative, rather than waiting until they're in hospital. (PIC).*

*..having the initial guided conversation when someone is in hospital, they're too poorly for that, you're better off trying to identify those people that are at risk and talking to them before they're admitted and doing it that way, and going, 'ok what can we do to support you?' and to put in structures and support then so that if they do get admitted then they'll naturally come out faster because you've already got that. (GP).*

### 3.4. The Role of the PIC

The role of the PIC itself was a very fluid sophisticated role which demanded a variety of skills and knowledge and was regarded rather like an enhanced healthcare role or “old-fashioned OT”. The evaluation particularly highlighted the demands of the role of the PIC, with the ability to navigate and negotiate a way through the health care system a vital skill which was crucial to the successful implementation of the project. The importance of a PIC's networks, contacts and knowledge of what is available in the local area and community was also emphasised, as was the need to spend time getting out and about in order to build local contacts and knowledge.

*I think you have to be medically aware of certain conditions and ageing, there's lots of things you need to be aware of....it's also about being aware of [how] the individual services fit in and then what's out there in the community. So, it's more than, if I was to write that job role, you have to be a social worker, you have to be a community matron but on the other side you have to be a community maker. (PIC).*

*You've got to do your groundwork and what was a benefit for us when we started in this year ...cos we were going to a new area, it allowed us to go down and do some groundwork, meet people, say who we are, this is what we do, nothing to do with the surgery but maybe the churches, and this and that, and that was really beneficial, doing that groundwork. It's always who you know not what you know. (PIC).*

### 3.5. Risk Stratification Tool

The Cornwall PCD Pathfinder operated for its first year without the RST in place. During these early stages it was not possible for GPs to identify patients in a systematic way and there was no way of knowing whether the service was working with the right people. This contributed to a feeling from some GPs that the PCD Pathfinder lacked clarity.

*...the way in which we'd envisaged and were advised it would be run is not happening cos of the stratification model not being there so we would like to have been able to identify those patients that [name of PIC] could then target in advance to ensure that all these things were done in a more timely manner, [name of PIC] is picking things up from ward rounds and from just being there and being available but it's not done in a systematic way, ...but I'm sure with a more systematic approach you'd be able to help more patients more effectively. (GP).*

PICs had to use their experience and work in an alternative way to identify people likely to be eligible for the PCD Pathfinder.

*At the moment we're just picking up anybody from those surgeries, whether or not that is right for this I don't know, but we don't have that tool. (PIC).*

*We don't know, we're literally picking, if we see anybody from those surgeries and they're over 50 we're taking them, whether or not they go the whole journey is dependent on lots of different factors. (PIC).*

Not having the RST in place impacted on the running of the project as additional work was created liaising with hospital staff and going through patients' notes. Without the tool there remained issues of patient confidentiality and the service was reliant on a great deal of good will from hospital staff and GPs.

*There's been an enormous amount of time spent with coordinators going up to the hospital, trying to identify people, there isn't an easy way to do that, it's a matter of trying to identify two or three wards. (Local Age UK).*

*We're fortunate that the staff have been so supportive, they've allowed us to go through people's notes because on their screens it doesn't show up which surgeries people are part of or even what area they're from, there's a name and an NHS number and a condition, so from that we have to go through the notes physically, 30 on a ward, you can go round for two hours and not have identified anybody, so an enormous amount of time has been spent looking, which has been demoralising at times, frustrating that you could go and spend half a day there and really not having come out with anything much. (PIC).*

*The surgeries are trying to help, most of them are trying to help really well, there are problems around the confidentiality as well, that if we have lists which they receive every day for admissions, we then are seeing people that are planned admissions, new borns, paediatrics, and that again is time consuming, looking through those where we've had those lists available, not all the surgeries are happy, we understand that, cos of confidentiality. (PIC).*

The lack of the RST also made it more difficult to monitor and evaluate the impact of the service.

*It was just get in there and start seeing people so that's what I did but that didn't, that's fine but you get to the point where actually what am I doing, who am I seeing, what's the methodology, all these things keep coming up. (PIC).*

*It's just that we don't have the outcomes from that aspect of the project, which would be much more interesting cos that can then potentially get rolled out on a much bigger scale and help more patients in other areas. (GP).*

After the first year the Cornwall PCD Pathfinder proceeded with just one GP surgery with the RST in place. Working more closely with one GP streamlined the process and enabled one PIC worker to identify patients at the GP surgery whilst the other two could concentrate more at the hospital end of the project.

For the PICs having the RST helped cut down on some of the running around in hospital needed before, but it did not necessarily overcome the problem of inappropriate referrals. For example, sometimes patients identified were ineligible or too ill for PICs to begin working with or patients didn't want help.

*It certainly stopped a lot of what we were doing in the first project, which was almost wandering around the hospital aimlessly really; it stopped some of that. (PIC).*

*We also found quite often that the people that it identified were inappropriate, they could be end of life or they could be too young for the project. (PIC).*

*...when we did identify people and we got them at the hospital, often they didn't want our help and it seemed to break down into groups. The people who are born and bred in Cornwall in that area..... they've got family support, they've got their sons and daughters, their grandchildren and things like that, the ones that were in most need and did access the help, were the ones that had retired down here so their family was still up the country somewhere or they've lost their partner or whatever and they were isolated.(PIC).*

There was a feeling that the process of identifying patients with the tool would still have been enhanced from having input from people on the ground. Working closely with the Onward Care team was just as effective.

*So, I wonder whether there was a lot of reliance on DOCOBO when there was a lot of information in the people on the ground, they had a lot more information cos they were with these patients. (PIC).*

*Yeah, if you combined it with say a community matron, if somebody just looked at the list and said, 'that would be a good one', give a bit of a human eye, a bit of knowledge to it. (PIC).*

*I would much prefer to work with onward care, cos they're the people charged with discharging these people from hospital and it's a very difficult task when there's no care packages in place and things like that, so from that point of view I'd like to work more closely with them. (PIC).*

In practice, PICs identified and worked with the similar patients with and without the RST. With one GP surgery, sufficient project capacity meant that PICs could work with most patients who were in hospital registered to the GP practice rather than rely on the tool.

*It was also to the point that we had three PIC workers and we were dealing with four or five admissions a day, so not a huge number of admissions, of which there was sufficient capacity within the team to basically work with everybody that was admitted, so in effect it negated the need to use the tool, purely because we had the capacity. (GP).*

One issue raised was about interpreting risk. The PCD Pathfinder concentrated on getting the RST up and running and using the tool but there was less attention given to how this risk might be interpreted. Whilst the tool was able to identify a broad group of patients who might be at risk of having a delayed discharge, the PCD Programme didn't define what the risk was or the appropriate risk level for intervention.

*I get the point around the stratification tool, because as part of the programme we hadn't decided where, we talked about people having a risk of being a delayed discharge, but actually what sort of risk, we hadn't defined that. (GP).*

*So it's how do you use that tool, cos in effect we were given the risk stratification tool and said 'there you go, get on with it', yeah we were taught how to use it, but as well you need to be taught how to interpret it....It's about trying to narrow it down to target a population, now in effect we've put the first lens on which has narrowed it down to a broad group, ok then what lens do we then need to put on to focus it even more. (GP).*

The RST offered tangible benefits for the GP surgery using the tool by enabling the surgery to interrogate its patient population which was helpful in managing and planning demand.

*Because it gives you a different set of eyes looking at the patient population. It's never going to be 100% accurate cos you're dealing with people ... but it does give you more of a chance of understanding where is your demand going to come from. (GP).*

The RST also enhanced opportunities to develop new ways of working by helping inform the development of services. For example, the surgery was able to reduce prescribing costs and spend in the practice, by utilising the tool to identify patients at risk of poly-pharmacy, reviewing these cases and improving the quality of prescribing.

## Benefits and Impacts

### 4.1. Perceptions of the PCD Pathfinder Programme

When asked about the PCD Pathfinder, stakeholders saw the project as a "bridge" between patients leaving hospital and returning home into the community. By providing support afterwards and working with patients once they were at home, the service was designed to help those at risk of hospital re-admission find other ways to access help, rather than be so reliant on further visits to their GP or hospital.

Specifically, the PCD project helped to do "the joining up bit" between different services, "every service has its remit, but nobody does the joining up" (PIC worker). The presence of PIC workers on hospital wards and at GP MDT meetings helped to link the range of health professionals involved in a patient's care, informing health professionals about available community resources and connecting the patient to community support.

*I have an MDT every week with my surgery, I tell the staff, not just GPs, it's district nurses, adult social care in the community, primary care dementia practitioners, physios, OTs, emergencies teams in the community, so I tell them who's gone in and what the plan is for discharge and the background of who those people are. (PIC).*

*The good thing about meeting the GPs at this weekly MDT is that I'm getting a lot of information quite quickly and pass that back about the people that are being discharged and that's where it's really useful cos you've got the district and community links and the practice nurse, so I'm saying somebody's coming out, it's not the ones that are high risk necessarily, it's ones that are bubbling under and may go back in if we don't put some preventative things in place. (PIC).*

As such, the PCD project and the way in which PICs worked helped tackle the silos which can exist between different healthcare and social care teams.

*We have large numbers of different teams all working in silos. There have been huge efforts in various ways to try and break down those silos and get people to work together in ways which is better for the patient. I'm sure you've been given lots of examples of different situations where someone like [name of the PIC worker] has helped. (GP).*

*We weren't sort of bound by department procedures, like the ambulance service have theirs etc., we were flexible and so we could ring the social workers, ring somebody else up and say this guy needs more help than he's getting...(PIC).*

As well as linking GPs and other services the PCD Pathfinder connected back into the hospital providing information on decisions and updates on patients' care. For example, PICs informed GPs about why certain decisions about a patient might have been taken at hospital, provided vital feedback on a patient's home and family circumstances and updated hospital teams on a patient's progress at home.

Overall, the PCD Pathfinder was seen by stakeholders as a means of getting people to work together in a way which was likely to be better for the patient, improving both the patient journey and experience.

## 4.2. Benefits for Staff and Other Services

An important feature of the PCD Pathfinder was that it provided a means of sorting out the "little things" that can often delay discharge or prevent a patient from going home to a safe environment.

*... it's all manner of little things and if you've just got someone who can do those things the patient has a much better experience, they're not left hanging around in hospital waiting for discharge or waiting for medicines or waiting for someone to bring the cat home, even to turn the lights on and get the house warm and put a pint of milk in the fridge or whatever it is that would assist that patient. (GP).*

The ability of the PICs to respond flexibly and work between services enabled them to solve problems that were often outside the remit of hospital staff and could hold up discharge.

*I did find it beneficial working in a hospital with onward care cos they were charged with getting these people home, and they were trying to do it as well, like with this chap I just mentioned, they were trying to do it but without the ability to perhaps go and visit the house beforehand to make sure there was food there, to make sure... and that's where we had the flexibility. (PIC).*

There was added value to having the PIC worker on the ward for the hospital. For example, in one case the PIC helped with a homeless man who had been admitted to hospital and could not speak any English. He could not be discharged because he had nowhere to go to. The PIC took his wife to the housing department and was able to help get the situation sorted so that the couple could be discharged to hotel accommodation.

The ward manager at one hospital also felt that the PCD Pathfinder and the presence of a PIC worker on the ward gave ward staff greater confidence and enabled them to be a little less risk averse when discharging patients. The PIC provided a vital link and the ward staff knew that there was back-up and continuity for patients at home after their discharge.

However, GPs and PICs did not necessarily feel that the Pathfinder was reducing the length of hospital stays or supporting people getting out of hospital sooner. One reason for this was the amount of time it was taking to get care packages in place at the time.

*...certainly in this area of Cornwall we have a massive issue with care packages, we cannot get packages of care for patients at home so if there's a patient in hospital that [name of the PIC] is looking to assist in reintegrating back into the community and helping them to get home, without that extra support from a carer, it's just becoming very difficult. (GP).*

It was acknowledged the programmes like the PCD Pathfinder have little control over aspects of the way the system works, and it was therefore difficult to detect what difference the PCD Pathfinder was making in expediting discharge. For example, one of the hospitals in which the Pathfinder was operating went into special measures. The hospital adopted emergency planning procedures which increased authorisations for care packages. This sped up discharge resulting in some patients being admitted and discharged before the Pathfinder had chance to work with them.

*...they had the gold command going virtually for the whole time that the project was running, so it was really hard cos we would identify people, cos each morning we get an email list of everyone that's been admitted and who's in the hospital, ... the PICs would go looking for them, cos we also knew which ward they were on, would go directly to them and then they'd go 'care package has been sorted, they've gone'. (GP).*

Whilst the PCD Pathfinder could get on and do many of the simple and little things that help patients leave hospital there remained gaps and obstacles in the way the system works which required higher level integrated working to overcome.

The ability of the PCD PICs to do “*the joining up bit*”, to ensure the care and support a patient was receiving after discharge was appropriate, was aligned to a community navigator role. The PICs benefited other services in various ways, for example, being able to identify what agencies were involved in a patient's care, highlighting any duplication, filling in gaps in provision and notifying agencies if action was needed. In one case, social workers referred a man they were trying to discharge from hospital to the PICs because he was concerned about water in his house. When the PICs visited the man's house, they were horrified to find human faeces up the walls, in the hallway and the bedroom. The man had been taken to hospital by ambulance, so the ambulance service had been in his home, he was known to the fire service because of accidents with his cooker and yet the onward care team were unaware of the situation as no agency had reported the issue.

*...he was living in this state and nobody was aware of it, or nobody had actioned it, so we brought it to their attention and in the end the property was deep cleaned and all the stuff thrown [out] and we had to source some replacement furniture and things so he could eventually go home. So, things like that certainly made a big difference. (PIC).*

The role of the PIC involved spending a lot of time building and strengthening relationships across a range of different agencies and with working alongside NHS staff.

*I think the relationships we've been building at the hospital and especially at the surgery they've developed even more so we've got quite good partnership working. (PIC).*

*I think it's just reinforcing the relationships within the different services from hospital and primary care, it is a very big job cos you've got the hospital side and you've got the primary care side. (PIC).*

These relationships helped to develop trust and break down barriers between services.

*...when we first started they didn't even open the door to us at the hospital, the door would open a little and it would be 'who are you, what do you want?' and we can ring them up now and they'll say 'oh hello, how are you doing?' that was*

*one of the successes, breaking down those barriers with social services and things. (PIC).*

*...it's just about knowing people rather than being faceless, if you know somebody and can put a name on it, they can often point you, you can cut corners by knowing people. (PIC).*

Having a PIC as part of the MDT also benefited other services through greater information sharing and improved knowledge of services available in the community.

There were benefits, too, for the staff themselves in undertaking such a rewarding role and seeing the difference they could make.

*I think it's very rewarding....to see the difference that they can make with small things, it's not enormous things that make the difference, it's those small steps and being able to support them [patients] on that journey home, to see them at home and be able to have photos of some of them that are fed back to the staff to see that fulfilment as well for staff, I think it's important for their morale. (Local Age UK).*

*I think it's very rewarding and it does benefit the patients, they feel reassured that there's somebody who can join up the dots and get support or whatever might be needed. (PIC).*

As mentioned earlier, involvement in the PCD Pathfinder and using the RST as part of the model helped to inform demand management at the Veor GP surgery and enabled the surgery to take a new and innovative approach to service development.

*I've also used the DOCOBO system [RST] to go ok this is giving us a good impression of what our demand looks like, what skill set do I need to have within the clinical team and the wider team to be able to satisfy that. (GP).*

*Actually, from a business point of view how can I devise services that intervene earlier with people so that they don't generate a dependency on our primary care service? (GP).*

The tool was so useful that the surgery successfully applied for a grant to commission it for another year and is in ongoing discussions around its future use and rollout.

The PCD Pathfinder Programme also helped to shift understanding and contributed to a cultural change in ways of working across the entire practice. This resulted in the development of new models of care which involved the voluntary and community with clinicians in a new way.

*So we're taking the practice out but also bringing the community in, so our vision for this place is for it to be a community centre which just so happens to have clinicians hanging round, but also within that clinical framework I've got a combination of nurses, doctors, pharmacists, care practitioners etc. that can all have similar but slightly different conversations with people. (GP).*

There was a feeling that overall the PCD Pathfinder had raised the profile of the Veor surgery and assisted with the development of the surgery being at the forefront of social prescribing activities.

### 4.3. Benefits and Impacts for Older People

The evaluation conducted five detailed case studies over a six month period with older people who were supported by the PCD Pathfinder Programme. (One participant was unable to continue in the study for the whole six month period so data is included up until the time they left the study). All cases had complex health and care needs and were socially isolated and lonely. Detailed case studies are included in Appendix A1 of this report. Common findings across the case studies are detailed below.

Our evaluation findings indicate that every effort was made to ensure that the older person went back to a home which was adequately prepared to meet their needs, helping improve the patient journey and their experience of the transition from hospital home.

The service provided gave reassurance and familiarity to those people leaving hospital.

*...they recognise you from hospital and so cos you know some of those teams, the actual people, you can explain who they are and what they do and where they fit in. (PIC).*

*Reassurance really, this is a period of transition now, you're recovering and this is what's going to happen and then we can look longer term if there are other things you want to do. (PIC).*

In particular, the support provided was extremely responsive and flexible. PICs worked creatively to get things done quickly and facilitated practical help and support which often goes a long way to helping to meet complex needs

*...she'll [the PIC] help you with what you want done if it's possible. (Case study participant).*

The approach taken was also respectful of an individual's dignity. In situations where a person's health was deteriorating and dignity was becoming an issue because of problems with hygiene or toileting, PIC workers responded sensitively identifying practical solutions which helped to make conditions easier to deal with and enabling people to maintain their feelings of self-respect.

Our evidence shows that many of the small things that PICs do usually lead onto much bigger things, often having beneficial impacts on the daily lives, social isolation and wellbeing of the people they are working with. In one case where a person had been falling due to alcohol consumption and was drinking to overcome loneliness, the PIC's practical support, advice about drinking and help to attend a local Day Centre resulted in him feeling much *more "positive about life"*, reducing his alcohol intake and consequently having fewer falls *"I'd rather not have any alcohol and still be on me feet."* (Case study participant).

The service enabled people to achieve their goals, for example, socialising and getting out and about more, visiting Day Centres, accessing befriending schemes etc.

*...she [the PIC] came to me and seen me and told me what was what, and they took us out, we went one day, it was beautiful weather. (Case study participant).*

There were also examples of the service intervening in ways which were likely to reduce risk and prevent further harm. In one case, where a gentleman struggled to get out because of a heavy wheelchair and a heavy oxygen device, the PIC

contacted oxygen suppliers to request mobile oxygen equipment which was easier to carry and with shorter tubing to prevent trips and falls. The problem was rectified the next day.

The support from PICs also helped people to improve the management of conditions and diseases like diabetes. For example, PICs encouraged and supported clients to visit their GP and also to attend clinic appointments by showing people how to book transport to travel to appointments and enabling them to book their own transport in the future.

#### **4.4. Measures of Success**

This evaluation is a small-scale qualitative evaluation and given the limitations highlighted earlier it has not been possible to provide extensive evidence on each measure of success for the PCD Pathfinder Programme. However, the evaluation evidence points to the following.

##### ***Does the involvement of Age UK staff facilitate better communication e.g. between GPs and hospital?***

Evidence suggests that Age UK staff do help to facilitate better communication between GPs and hospital and community teams. Much of the PIC's role involved building and strengthening relationships and developing trust within services and between different partners and agencies. The Age UK team overcame barriers by getting to know the appropriate hospital staff and teams and demonstrating that the work they were doing made a difference. The ability to respond flexibly in meeting many of the non-medical patient needs which can hold up discharge, and which were outside the remit of hospital staff, helped demonstrate the value of the service. Being part of a GP surgery also helped hospital staff take the project seriously and provided a vital link. The presence of PIC workers on hospital wards and at GP MDT meetings connected the range of health professionals involved in a patient's care, improving information sharing and highlighting patient concerns and updates. Working closely with an older person and acting as their advocate enabled PIC workers to elucidate the individual's preferences, wants and needs in a much more meaningful way to the professionals involved in the older person's care. Stakeholders widely regarded this way of working as likely to improve the patient journey and experience.

##### ***Are PICs able to influence how quickly someone is discharged from hospital and where they are discharged to – reducing extended LOS and premature care home admission?***

There is little evidence to support the notion that PICs could influence how quickly someone is discharged from hospital. Stakeholders pointed out that Programmes like the PCD Pathfinder have little control over aspects of the way the health and care system works, and it was difficult to detect what difference, if any, the PCD Pathfinder was making in expediting discharge. The amount of time it takes to get care packages in place was given as an example of why such a project might have little effect. During the evaluation period, one of the hospitals in which the Pathfinder was operating went into special measures and emergency planning procedures were put in place increasing authorisations for care packages and speeding up discharge which resulted in patients being treated and discharged before the project had chance to work with them.

***Can PICs help make the discharge process reflect the older person's preferences and situation? Can they make older people feel more comfortable about being discharged?***

However, it is clear that PICs were able to aid an older person's transition back home, providing information and discussing concerns, dealing with non-medical issues and barriers that can hold up discharge and making every effort to ensure the older person returned to a home environment adequately prepared to meet their needs. PICs gave much needed continuity and reassurance to those leaving hospital, acting as "a familiar face" and ensuring that older people knew they would be supported and receive ongoing help once they returned home. PICs also provided reassurance to older people that somebody was acting on their behalf and helping to coordinate care to meet their needs.

***Are PICs able to improve the wellbeing of older people once they are out of hospital in a sustainable way?***

The case studies highlight the benefits and impacts for older people delivered by the PCD Pathfinder which helped to improve their wellbeing and ability to cope at home - a number of the older people we interviewed reported feeling much more positive about life as a result of the intervention. After leaving hospital PICs supported older people in a holistic way, working responsively and flexibly to meet a range of practical, social and care related needs. A holistic understanding of these needs was often gained via the guided conversation led by the individual the PIC was working with. Older people frequently needed a longer period of flexible support than the 8-week support timeframe proposed for the PCD Pathfinder Programme by Age UK. The guided conversation and the flexible approach taken to working with an individual enabled PICs (as well as other health professionals they were working with) to develop a greater understanding of the older person's needs and aspirations. In all, the Pathfinder supported 151 individuals through guided conversations, signposting and support.

Most people that PICs worked with were recently discharged from hospital, had co-morbidities and other complex needs and were typically lonely and socially isolated. A major issue was supporting people to (re)connect with their community and providing ongoing additional practical help and/or signposting to do so. Support often focussed on helping older people build confidence and motivation to ease feelings of loneliness and isolation. An important aspect of PICs' work was helping older people to realise their goals for much needed company and to get out and about more through befriending schemes and other activities like attending Day Centres.

The PIC's role in assisting older people to access practical help and support in order to better meet their complex needs was also a vital part of their work and this help was often invaluable in managing longstanding conditions and enhancing the quality of life of older people. Examples of the type of support that PICs were able to put in place are detailed in the case studies. It was apparent that many of the small things that PICs did for individuals usually led onto much bigger things which often had beneficial impacts on the daily lives, social isolation and wellbeing of the people they were working with.

The approach taken by PICs and the variety of support, options, choices and services offered helped older people to try out opportunities and build solutions that were more likely to work for them. Although evidence is limited, building suitable services and options around the individual may increase the likelihood that they will continue to benefit from support, and possibly, help deliver more sustainable improvements in wellbeing.

# Learning and Conclusion

## 5.1. Learning

This evaluation highlights some of the challenges for the PCD Pathfinder Programme and suggests learning which may be beneficial for future Programmes.

As well as illustrating the considerable time, effort and persistence required to set up such a Programme, **the experience of both PCD Pathfinders demonstrates the importance of finding a key person or advocate who can authorise decisions and make things happen.** Although both local Age UKs have experience of working innovatively with a range of partners in General Practice, health and social care it still took time to develop relationships and gain the trust necessary to introduce the project, its purpose and the staff roles within it. There was a feeling that third sector organisations must work much harder to prove their worth and that not being from a medical background can create barriers to working with medical teams. **Evidencing how the Pathfinder could make a difference in helping solve some of the problems that Hospital Trusts are facing in meaningful and understandable ways was beneficial and helped with project 'buy-in'. Being recognised as part of a GP surgery was also important and helped hospital staff to take the project more seriously.**

A major issue for the PCD Pathfinders was working with DOCOBO and developing the RST. Information governance and particularly getting authorisations for data sharing and linking were considerable challenges which caused both Pathfinders significant delay. These delays often resulted in GP partners losing enthusiasm for the project and a loss of project momentum.

**For such Programmes to proceed therefore, it was vital to have someone who understood information governance, risk stratification and could link to other business and service opportunities.** In Cornwall it was only possible for the PCD Pathfinder to start operating with the risk tool in place once the Veor surgery got involved. The Veor surgery Strategy Partner understood the technical requirements and was able to take the lead on these elements, working closely with DOCOBO and the development of the RST. Without this input it is doubtful whether the Programme would have got started.

Factors identified which helped to facilitate data sharing arrangements were:

- Awareness of the legal framework for sharing data and legal precedents around sharing patients' medical records if data is to be used for delivering improved clinical care.
- Checking the compatibility of data systems.
- Ensuring Age UK staff have honorary contracts with the GP practice so that they can use the data analysis, providing appropriate safeguards are in place.

- Understanding the technical requirements of the tools that are being used.
- Making sure issues around consent are understood and handled sensitively.

The emphasis of the PCD Pathfinder was to get the RST up and running and less attention was paid to how risk might be defined and interpreted. The PICs working in hospital settings still felt that the risk tool would have benefited from the expert input of people working on the ground. **More thought was needed around how the tool and the PCD model could be best embedded into MDTs.**

Once operational, **having the same people regularly attending the hospital helped hospital staff recognise the Age UK PIC team and was beneficial for developing relationships. The importance of PICs being a visible presence on hospital wards and having a proper base at hospital was stressed as this helped provide continuity and build relationships.** Working in a large hospital was a challenging experience and it took time for PICs to become accepted, make key contacts and feel part of the team. **Getting to know teams such as Onward Care, Rapid Response and Rehabilitation was particularly useful as they know who is being discharged and understand the complexity of discharge. Such teams are often willing to work with a project like the PCD Pathfinder as they see directly the difference the PICs make.**

**The significance of building relationships and gaining trust cannot be over emphasised and it was apparent that a great deal of the PICs' time was spent strengthening relationships across a range of different agencies and with working alongside NHS staff.**

**PICs also spent much of their time supporting people to (re)connect with their communities. PICs' local contacts, networks and knowledge of what was available in the local area and community was of vital importance. It takes time to acquire such knowledge as there is often a wide range of volunteer local led activities out there. If there are no up to date directories or databases of local support PICs may need to spend some time getting out and about building local contacts to develop such knowledge.**

Age UK recommended a two-month period for working with older people. However, those people requiring ongoing support needed a much longer time period. Whilst a timeframe can be useful when setting goals one of the most important things was to be clear about the relationship. **Ensuring the individual was aware of the amount and type of contact they would receive and that support or information to access support was available to the individual when the PIC moved away or signposted onto other agencies was essential.**

**Developing simple consent and privacy processes and taking a sensitive approach to gaining consent is of particular importance when working with people who are vulnerable.** Given that those the PCD Pathfinder was working with were often in hospital at first visit, people were sometimes reluctant to give consent for this programme because of feelings of vulnerability or confusion. Consent for the PCD Pathfinder ran at about 50% and was generally quite low in comparison with other similar Age UK programmes and pilots.

## 5.2. Concluding Comment

Overall, the evaluation provides evidence that the PCD Pathfinder Programme has led to positive change for those involved including improved wellbeing for older people, enhanced opportunities for developing new ways of working and informing service development within the GP surgery in which it operated. However, both

Pathfinder areas experienced challenges and delays in establishing the Programme and in setting up the risk tool which was vital to the development of the Programme. One of the Pathfinder areas, North Tyneside, did not go ahead as planned. Due to these challenges and delays it was not possible for the evaluation to gather as much data as intended. Less evidence on the benefits and impacts for older people was gathered and it was not possible to compare the different models of delivery to identify what worked well in each site and where improvements could be made.

Although there are limitations to the evaluation which mean that the results should be treated as indicative, the findings do point to the Programme achieving the following measures of success:

- The involvement of Age UK staff does facilitate better communication e.g. between GPs and hospital.
- PICs are able to help make the discharge process take account of the older person's preferences and situation and make older people feel more comfortable about being discharged.
- PICs are able to improve the wellbeing of older people once they are out of hospital in a sustainable way.

However, the evaluation suggests the PCD Pathfinder had little impact on how quickly someone is discharged from hospital as such programmes have little control over aspects of the way the health and care system works. Despite the challenges that exist with lack of care packages leading to delayed discharge and which are outside the control of the Programme, it was apparent that PICs were able to bridge and support other services and add considerable value. Overall, our findings suggest that organisations like Age UK and the voluntary sector can make a positive contribution by providing support to older people in an acute setting, and especially supporting hospital discharge.

# Appendix 1: Case Studies

## Bernard

Bernard is a 73 year old living alone on the third floor of a block of flats in Cornwall (these are privately rented). Bernard's partner passed away in April 2017. He has two married sons and young grandchildren who also live in Cornwall but doesn't get to see them often ("*they haven't got the time*"). He has a close friend living nearby. Bernard is retired and formerly worked in furniture retail. Apart from a pacemaker, Bernard is in reasonable physical health and is able to drive and get out and about but is currently suffering from anxiety and panic attacks.

Bernard came to the PCD project after a spell in hospital following panic attacks. Bernard has lived in Cornwall for approximately 16 years, initially in a bungalow, but since his partner went into care, he moved into a third floor flat. The flats are not specifically for older people and there is no lift to the upper floor, and although Bernard manages the stairs now, it could become a problem in the future. The occupants of the flats are from a diverse range of backgrounds and ages and Bernard has not formed any friendships with any of the other residents. Bernard's partner died on the 11<sup>th</sup> April 2017 and since then he has been struggling to come to terms with the loss, the loneliness and the isolation, which he feels is worsened by the current living arrangements. His flat is in a fairly isolated location. Despite having some family in Cornwall, he feels desperately lonely and suffers with anxiety and panic attacks.

*"It's a very nice flat, I'm happy there, but it's very steep slopes so it's not very suitable."*

*"There's a little agency, part of Cornwall's Council that specialize in sorting out people's housing needs for the over 60s so X [my PIC worker] is helping me with that [...] I'm on Cornwall's housing register, social housing, and I've been through an exercise with them."*

Age UK Cornwall allocated a PIC worker to visit Bernard who has worked with him to explore ways to combat the loneliness and look at alternatives to his current accommodation. He became aware of Age UK through their involvement in his wife's care.

Bernard wanted Age UK to help with sorting out his housing situation, i.e. to find more appropriate accommodation. He also wanted help with finding other types of social activities to get him out of the house more and keep him occupied. Bernard used to go to pottery classes with his wife and wanted to start this up again. At our initial interview, and since his involvement with Age UK, he had started a pottery and art class which he went to every Wednesday. Age UK also introduced Bernard to the PEAT Project, where he helps with gardening and meets other people.

*"There's no pressure to go, you're not committed to anything... you can just go in there and have a cup of tea if you want."*

Bernard's health had been suffering since his wife passed away, and he felt that he needed greater support around grieving.

*"Grieving is something that they clinically don't take any notice of cos it's personal and everybody's different so they can't generalise on it."*

At our **6-week catch-up**, Bernard had started weekly private counselling sessions, which he said had been helping him. He continued to go to the community-run pottery/art/reiki/therapy classes. He had joined another art class as part of the University of the Third Age. To help address his isolation, Bernard had signed up to West Cornwall Buddies, and was waiting to be paired up with a match. He had been attending coffee mornings - something which he used to do with his wife - and through this, had become reacquainted with an old friend who he hadn't seen for a long time.

His housing situation was progressing but quite slowly, Bernard reported. He had gone through an initial assessment but was having to be reassessed as a result of being a private tenant.

At the point of our **91 day / 13 week interview**, Bernard was still pursuing his social activities to keep as busy as possible *"and fill all the gaps"*:

*"I'm doing all that I'm trying to fill all the gaps because I don't like being stuck in the flat on my own. I have a full day for my pottery day and then there's an art club that I go to now as well. I've got other things as well, they do luncheons and things. The Carbis Bay Association has got their act together now and they've relaunched it and they're doing regular lunches out so they're good. I think the last one I went on, I think there were about 20 people who went, so I'm enjoying that."*

Bernard had been trying to move from his current private rented flat (with steep stairs) to a more suitable social rented property. He wanted to move back to Carbis Bay where most of his family were. This had been progressing slowly since our last conversation.

*"I've got the feelers out now to move back to Carbis Bay when it's possible [...] It's now sort of been processed. So, it's a matter of time, though it could be a long time I think. Because mainly it's for people who are going to be homeless. Now I'm in private renting, and I can afford to be private renting. But I've got two flights of stairs and they're really steep, so they've been accounted. It would be so much easier and better for me if I was living back there. It's only 5 or 6 miles [away from here] but the thing is with where I am now I have to get in the car to even get a paper. I could walk down but it's too steep to walk back."*

*"I know people in Carbis Bay we lived there for 18 years you see. So my life would change completely if we went back there [...] I've got a guy whose job... they're a little unit in Cornwall Council that specialise in looking after over 55s and ensuring that they're in the right accommodation."*

Bernard was still attending bereavement therapy and felt this was helping him cope better with the loss of his wife: "I did it privately so it's costing me £50 a week. It won't be for long but... it's worth it because it's excellent. The lady is very, very experienced. So that's working and I'm really pleased with it.

*Interviewer (I): Have you noticed the difference in how you're feeling after that?*

*Respondent (R): Yes, because she gets, manages to get, out of you things that are just sitting... I don't know it's just the way she works; she'll drag out stuff that you've sort of hidden away."*

Bernard had signed up to West Cornwall Buddies after the suggestion from his PIC to try to meet a like-minded companion and address his isolation.

Last time we spoke Bernard was waiting to be paired up with a match. This hadn't worked very well for Bernard, but he was keen to try it again: *"I was actually paired up with a lady. She was fine, she was in the same situation as me, she'd lost her husband and all that but she was a bit 'School Mam-ish' and it put me off [...] the idea's good [...] if they come up with anything or find somebody then I'd be quite happy to try because it's the worst part of my life is the isolation"*.

Bernard still receives support and visits from the Age UK PIC:

*"Yes, because [name of PIC] is still there you see, my Age UK worker.*

*I: When did you last see [name of PIC]?*

*R: Last week or the week before, he's been on holiday. He's there so any queries and he's there and he comes up with ideas as well. So, it is handy and it's also somebody to talk to as well because I'm pretty isolated. The thing I want in my life is companionship"*.

*"When Leslie died [name of PIC] X was very close to Leslie and her main carer. And] she's [the carer] taken me under her wing. And she just pops in every now and then or I phone up and then it just keeps me... she's very good. [...] After Leslie died, she kept coming, just at odd times, to check that I was alright and have a natter. That's made a big difference to me."*

Bernard told me for the first time that his brother had been diagnosed with bowel cancer. What made this worse was the fact that Bernard could not visit him:

*".. because of the risk of transferring infections so that's a sickener really. My brother is in Scarborough and all their family are in Derbyshire so I do like a grand tour, but I can't do that now you see, I can't go up to Scarborough at all because of this worry about transferring anything. If I can't go to Scarborough I can't go to Derbyshire because it means I'll be paying out twice for my fare, so I've just got to be patient now and wait until my brother finishes his chemo. I mean everything's very positive but as I say, I was hoping to go and see him, but I can't do it."*

At the point of our **18/19 week catch-up**, Bernard was under the weather with flu when we spoke - he had lost his voice completely the week before and was still struggling to speak. Bernard told me that he was currently awaiting confirmation of a diagnosis of Parkinson's disease - *"all the information's gone up to Truro and then I'm waiting for a response from Truro"*. Bernard had talked to his GP about all the different symptoms and he is quite concerned that he has it.

Bernard's housing situation had progressed somewhat, but he was still waiting for the opportunity to move to Carbis Bay to be closer to his family and within walking distance of amenities.

*"I've got a lead this morning so I'm going to follow that up. I want to get back to where my sons are in Carbis Bay and I can't cope with these stairs here [...] but this one has just come in. Somebody has just died, and it's my own landlord and it's a friend of hers, and they will be re-letting it. So, it's just a matter of waiting. The funeral, I think, is today so it'll be a few weeks like... With a bit of luck, I might get in there; it's a ground floor flat right next to a Costcutter and a post office and a bank, and everything's in walking distance. Because they've not taken the car off me yet, but I presume at some point they will do."*

Despite his health not being great over the past week or so, Bernard had still been getting out and about and attending social activities where he can.

*"I'm not right but I keep going and I need to go to these different things as well, otherwise I'm just camped here 24 hours a day which I don't like."*

Bernard had lots of plans for Christmas.

*"I've got three Christmases coming up. Two of them are in one day with my two sons and we're having one on lunchtime with one son and then afternoon/early evening with another son. And then I've got a lunch with the morning coffee people that I go to. Oh and there's another one as well, the pottery, they're having a Christmas lunch."*

Bernard confirmed that his visits from the PIC had finished now.

*"Their contract finishes, you see, at the end of the year. And hopefully they know that they're going to get a new contract but it's going to be different and they won't be covering our area; it's going to be a different area further up they won't cover me. I still keep in touch with [name of PIC]."*

**At the 6 month interview**, Bernard had just this week moved into a new ground floor apartment in Carbis Bay, which he has been waiting to do for a while. Bernard is now living in the same village as his family. He was much happier with his living situation though still in the process of unpacking and settling in. His two sons helped him move.

*"It's a nice flat, ground floor, walking distance to my son's, Cost Cutter is just down the road, and there's three restaurants nearby."*

*"Carbis Bay is quite a small community and they all knew from before that I'd lost my wife, so there's lots of people looking after me now."*

He was still sure that he had Parkinson's disease but was awaiting the full assessment, scheduled five days after the interview. *"There's no doubt I've got it because of the symptoms"*. He was trying to maintain a positive outlook and was determined he could keep up his usual active social life (in fact, was looking forward to the social events that might arise through Parkinson's support groups). *"Nowadays if you've got the willpower and the right backing you can hold it at bay, but we'll just have to see"*.

He said that he felt in good health despite the potential Parkinson's diagnosis. *"This Parkinson's is a shock but it doesn't frighten me or make me panic or anything"*. Bernard had been waiting a while for an assessment but looked forward to it being over with so he could move on and plan from there: *"They have quite a big social and information group in West Cornwall, and they all have meetings and social events so that's quite interesting, I'd get involved in that. It's a weird disease, it's sort of hidden... but there is actually a massive back-up facility, it's there"*.

Bernard had been suffering from intermittent depression since his wife passed away and had been attending private bereavement therapy to manage this. He had chosen to stop these sessions since we last spoke (just over a month ago) - it was expensive, and he felt he had got as far as he could with it. *"It became repetitive. And it's costing me £50 / week. It did really help me, it just started to become repetitive and I thought that's daft that"*. Bernard still had therapy through 'Space for You' at St. Just. *"I still go down there once a week for my pottery class, and they have a woman there who does therapy. She doesn't really do bereavement, but I've been going for a year now and it's good to get someone to talk to for an hour. We've got a good relationship so it's more of a social hour but occasionally we talk about in-depth things"*. From April/May, Bernard will be attending these classes at 'Space for You' two days a week. He is still going to a coffee morning once a fortnight, and the luncheon club.

Bernard has started seeing a volunteer carer who visits about once a month and takes Bernard out on social outings (she lives in Carbis Bay). *"She's not connected to any organisation; she's just doing it off her own back. She looks after her mother full-time and she does voluntary work in-between"*.

Other than speaking to the PIC now and again, Bernard's contact with Age UK had come to an end. Bernard still feels lonely and has periods of time where he doesn't speak to anybody. *"It's improved because I've got more activities"*.

Bernard feels like he could ring the PIC or Age UK if he needed help again.

He had more activities planned for the summer which he was looking forward to (going walking, going out for cream teas).

#### What difference has Age UK's intervention made to you?

*"It's got me out of sitting at home doing nothing, and isolation and the whole thing. [Name of PIC] was very good and came up with ideas all the time, 'try this, and try that'."*

*"I could quite easily have got so depressed that I needed a lot more attention."*

*"I'm sure I would [have been in hospital more] because I would have had panic attacks. Sitting in that bungalow on my own for days on end...there's no doubt it's helped me. I wouldn't have got away without having at least one more panic attack because you can't control them."*

Bernard was sure that he would not have taken up all the social activities he's currently involved in were it not for his PIC and Age UK pointing him in the right direction: *"Oh yeah, because you're not aware of anything that's going off in the community really. It's weird; nowadays people don't talk to each other"*.

*"[Name of PIC] was very supportive and I think he was - because I wasn't negative, it sort of spurs him on to help me."*

He spoke of the challenge to hold onto all the progress he had made and *"maintain a decent lifestyle"*.

## Richard

Richard is 70 and lives alone in a ground floor flat (rented from the Council). He has diabetes. He was admitted to hospital due to a fall. After a five week stay at West Cornwall hospital he was discharged when his care package was arranged. A walking frame was provided to aid his mobility. Although Richard prefers to remain in his home, and be cared for at home, he felt uneasy about leaving hospital and coping at home on his own. Carers were arranged for him by Social Services, at no personal cost to him. They provide support twice daily; 30 minutes in the morning and 30 minutes late afternoon. The social aspect of their visits is valued more by Richard than the practical help provided:

*I: "Does it make a difference having those carers?"*

*R: They don't do nothing but it's someone to talk to, if they didn't come in, I wouldn't see nobody."*

The carers help Richard to maintain his independence by assisting him to do things himself -

*"I have somebody coming in the morning to help me with me breakfast but that's to help, not do it for me and apart from that I do most things myself."*

However, he pays for a cleaner to help once weekly. Richard rarely sees his family or friends. He can take a taxi to the pub, where he enjoys drinking alcohol and it is this pastime that leads to falls, including his most recent fall, which has affected his mobility.

When asked how he found out about the Age UK PCD service, Richard struggled to recall how or explain how they were assisting him - he commented that information was perhaps received on the hospital ward.

### Telephone catch-up six weeks later

The carers were continuing to provide support twice daily - *"I've got someone to talk to"*. One of them takes him shopping to a local supermarket. Richard enjoys this because of the interaction with the supermarket staff.

He has started to attend a community Day Centre two days (Mondays & Wednesdays) each week, arranged by Age UK. *"I didn't really think it was going to be nice, but actually I've enjoyed it [laughs]..... they cook me dinner and pudding and stuff"*. Richard is picked up in the morning by a community mini-bus and dropped off home late afternoon. He participates in various activities, and light exercises.

The Day Centre visits are currently received by Richard as part of a care package, which is publicly funded, however, this will end in a few weeks and Richard will fund further visits himself. He will assess the affordability then but try to continue to attend the centre as he *"really enjoys" his visits*.

When asked whether he intends to continue to go to the Day Centre even when the PIC is no longer involved in supporting him, Richard replied, *"yeah, course I will. I enjoy going down there"*. He didn't initially want to go when the PIC suggested it, but once he went and talked to people, enjoyed the hot meal, and entertainment, he continued to attend.

Richard had been readmitted to hospital since the last visit in August, having suffered another fall due to alcohol consumption. The Age UK PIC spoke to him about this issue, and as a result Richard has considerably reduced his alcohol consumption - *"I'm not drinking anymore if I can avoid it"*. Although he didn't attribute this change to the PIC's advice. He also alluded to the fact that he was drinking to overcome his loneliness.

The PIC has helped Richard with practical tasks such as purchasing a new mattress and arranging a repair to his washing machine. Richard had thought about purchasing a replacement washing machine - however, *"It's working alright"*. When the PIC found out that Richard was missing his podiatry appointments she booked him some transport - *"yeah well she did it for me the first time, booked it for me the first time....I have to book it myself"*. He is fine paying for this.

The PIC visits from time to time, but Richard realises that her involvement is short-term and that he will have to continue to do things for himself. He recognises that she provided *"information"*, and arranged things for him, such as transport, which he will have to continue to book independently. She has also arranged for a cleaner to help (make the bed, hang out laundry etc.) for 30 minutes on Thursdays, Fridays, Saturdays and Sundays. Richard is managing to pay for the cleaner.

In terms of gaps in his care, Richard feels he needs help with his personal care e.g. to have his beard trimmed and his hair cut. Currently, he can afford taxis (£14 return journey) to and from hairdressers, but this may change.

### **Assistance from the Personal Independence Co-ordinator:**

- Raised discharge notes re: GP to review meds at weekly MDT;
- Check Diabetes clinic attendance;
- Check podiatry clinic attendance;
- Source repair for washing machine;
- Arrange laundry service while washing machine out of action;
- Reorganise lounge furniture as sofa not fit for purpose;
- Request codeine and Movicol from GP;
- Support Richard to purchase new mattress as existing very poor and giving disrupted sleep and bad posture;
- Register with Community Transport;
- Book Community Transport for Diabetes clinic as 2 years non-attendance & podiatry & accompany on first trip;
- Contact Early Intervention service as Richard struggling with personal care, next day another fall & admitted to hospital;
- Visited in hospital discussed alcohol consumption;
- Arranged for 6 week free sessions to local Day Centre;
- Sourced private help to include shopping and deep clean, weekly clean, personal care;
- Sourced protective leg covers to allow for showering.

### **The Personal Independence Co-ordinator reported:**

Richard is far more positive about life. He has made the decision to not drink after his last fall and is really enjoying the social interaction and home cooked meals at the Day Centre. He feels more confident to mobilise now he is supported by carers and enjoys being able to choose his meals. Pain is better managed, and he has a lower cost transport option. His sleep quality has improved, and he is now attending podiatry appointments which are important due to his diabetes.

## Interview at 91 days

Richard reported that the carers had withdrawn their service since our last discussion (6 weeks ago), allegedly due to inappropriate comments made by him. He was very upset - *"it's hard, especially when you've been told they won't come round here, and they won't tell you why"*.

In terms of his care, he is desperate to return to the old arrangement of somebody coming in two or three times a week, doing a bit of hoovering and washing for him -

*"Well I have nobody to do me cleaning for me, hoover up and all that sort of business like I had before."*

Whilst he no longer receives help with cleaning, somebody (not his carer) does his weekly shop and makes his bed. His PIC worker is off work, so he doesn't have anybody to take his concerns too. Not only is the practical support provided by the carers missed, but also the social aspect of their visits. Richard's isolation has been compounded by their departure as he enjoyed talking to them. His main source of interaction now comes from attending the Day Centre twice weekly, which he is now paying for himself and as of yet, affordability isn't an issue. He gets a hot meal and a bath. Although Richard didn't elaborate on the value of receiving a bath, his PIC had mentioned previously that he had been struggling to maintain his personal hygiene. Medical advice provided at the Day Centre also led Richard to reduce his intake of medication, and he felt the benefits - *"I've cut them down and it don't make me half as sleepy as it did.....I do feel a lot better"*.

Of most significance, resulting from his reduction in alcohol intake, he has had fewer falls, *"I think it has made a difference, I'd rather not have any alcohol and still be on me feet"*. Aside to the health and safety of the PIC's advice, Richard recalled her practical help, for example, in setting up a direct debit for the lifeline service that he uses. Richard appreciates her responsiveness, *"I've got her phone number if I can't get something, I can phone her up and she'll come out and help me out"*.

At this stage, there is evidence of where his care falls short, particularly in relation to his laundry *"they put it in [the laundry], they leave it, how am I supposed to get it out, that's my trouble, I can't get it out or hang it up"*. Previously, his carers did this.

During this visit I noticed shards of glass on the table and floor. It transpired that Richard had broken a glass but was unable to pick up all the pieces due to his inability to bend down for very long and difficulty with mobility. As he was no longer in receipt of regular carers' support there was an imminent health and safety risk, which I reported to Age UK immediately after the interview.

At the **point of our 18/19 week catch-up** within 24 hours of my call to Age UK they had sent someone to Richard's home to vacuum the rest of the broken glass up and dispose of it safely. Since the last visit, both of his legs have been bandaged due to scabs and sores, but he can get about okay.

Six weeks later, he still hasn't got any carers helping out daily. He explained that he needs carers, *"nobody makes me bed, or, changes me bed"*. The previous arrangement of support provided once weekly with shopping and cleaning continues. Richard explained that he receives ready meals from Wiltshire Farm foods, but he couldn't recall how long this arrangement had been in place. Since attending the Day Centre (usually twice a week) and eating there he has requested fewer meals to be delivered at home.

Community transport takes him to the Day Centre and back home again, he gets a meal, and they give him a bath - *"I enjoy it...I know a lot of people down there"*. The Day Centre is his main source of social interaction because he doesn't see anyone from Age UK anymore.

He did enjoy seeing the PIC. However, Age UK check up on him every few weeks - *"they ring me up now and again to see if I'm okay and that's about it"*. Richard doesn't recognise this as a type of support. At home, he watches a lot of television and he has managed to refrain from drinking alcohol, *"I just don't want to drink anymore"*.

During our **six month interview** Richard revealed that 3-4 weeks ago he had started drinking alcohol again. He recognises that the drink isn't doing him any good, but the loneliness at home drives him to drink, *"I'm on my own...what else am I going to do"*. Although he attends the day centre twice weekly, he commented, *"but I'm only going on Monday, Wednesdays - Tuesdays, Thursdays, Fridays, Saturdays, Sundays, I'm all by myself...I'm not seeing anybody, nobody comes down to see you"*. The short visits from the cleaners allow little opportunity for social interaction - *"all they do is a little washing up and away they go"*. When asked if he would like to attend the Day Centre more often, he stated that he could go more often but wants to lie-in some mornings; such visits require early pick-ups, followed by a long tiring day. Also, the drink makes him feel unwell, so he doesn't want to go out. Richard seems trapped in a vicious circle of alcohol abuse and loneliness.

So far, he hasn't been re-admitted to hospital, but recognises that he has been lucky as it is the drinking that previously led to falls and hospitalisation. The Age UK PIC previously helped him come off the drink, but he doesn't see her anymore - *"I think she's [the Age UK PIC] helped me to stay off the drink.....she used to help me with different things, I think she'd help me with my drinking as well"*. A general improvement in wellbeing was attributed to the PIC's help, *"I wouldn't have got a new mattress if it weren't for her"*.

## Rita

Rita is 79 and lives alone in a two-bed social rented house. She receives help from carers four times daily. The morning carer visits for 45 minutes and helps her to bathe, dress and prepares breakfast. Subsequent carer visits last 30 minutes each and involve preparing meals, getting Rita ready for bed etc.

She has suffered several strokes, a heart attack, and recently toe amputations, which contribute to her mobility problems. Rita also struggles with her memory, is unable to drive, cook and clean due to her health problems, and is largely housebound.

Every week, Rita is taken to her podiatry appointment by ambulance from her home, and, one of her carers occasionally takes her out for lunch. A library service provides books at home monthly. The Age UK PCD Pathfinder is involved in providing Rita support, but the exact nature of their involvement is yet to be determined. Rita is isolated; she sees her son and daughter-in-law monthly and she is no longer able to attend a heart and stroke meeting on Thursday mornings due to her amputations and bandaging. She was provided special shoes which fit over her bandages but after falling when getting out of a taxi she feels too frightened to go out alone.

When asked what she would like to do, Rita emphasises that she would like to go out:

*"I would like somebody to come and take me out, I don't know, anywhere. I have heard that there's a hydrotherapy pool here now and I used to love swimming and I'd like to try again cos I think that strengthens so much of your body."*

She recognises that a carer would have to take her to the hydrotherapy pool and the difficulty affording this:

*"That's why I say about going to the hydrotherapy and paying for somebody to come with me, and also sometimes going on a Thursday when I went, I had to have a taxi to and from, that's £10, it all adds up."*

Currently, she uses her personal budget to pay for the carers and she pays for a cleaner three times weekly as well as a dog walker.

Social Services have provided equipment to aid her independence, for example, a trolley that she can sit at and make herself tea. The Council fitted a stair lift in response to her increasing falls and immobility. Rita has had many falls which have led to her being admitted into hospital on numerous occasions. Her recent admission into hospital was also due to a fall. She doesn't remember Age UK speaking to her about the PCD service during this stay but was already known to them for other support.

Rita recounts her previous experiences in hospital as being unpleasant and distressing:

*"One time before that it was dreadful cos I went in with a stroke and I was on the heart ward for a day and it was very busy so they sent me to another ward and then another ward and I was moved at night so I didn't, well I wasn't with it and I remember laying there thinking this is wrong and everything seemed so small and I thought it was something to do with children, I was totally confused."*

She has only seen Age UK staff a couple of times since taking up the services of the PCD project. She hopes to be taken on more outings as this would improve her quality of life:

*I: "What does it mean to you, being able to get out?"*

*R: A lot.*

*I: How does it make you feel?*

*R: It makes me feel happier, just to see the countryside cos I used to love going round and seeing things.*

*I: And you're smiling when you are talking about it?*

*R: Yes, I do like that."*

Generally, she has little awareness of the support services available locally. She would like to continue to live at home and be cared for at home. With few family and friends to help out, the carers are best placed to deliver her care.

### **Observations on the day of 1<sup>st</sup> interview**

The fire alarm was consistently bleeping during the interview. The Age UK PIC responded immediately when she became aware of the problem. The text message received from her a couple of hours later the same day confirmed that the problem with the alarm was being looked into: *"Just popped into the fire station and they're on their way round to fit a new alarm now"*.

### **21<sup>st</sup> Sept 2017**

A brief conversation with Rita's carer revealed that she has started to take Rita out for lunch regularly on Tuesdays. However, she also mentioned that Rita hasn't been well recently, and her health appears to be deteriorating.

At the point of our **6-weeks catch-up**, the cleaners continue to provide help during the week as well as the carers providing support to Rita four times daily. She values them immensely - *"they're very good"*. She was taken good care of after her fall.

Rita confirmed that she hasn't been well. She has cellulitis (a skin infection) again and she has had two falls over the past six weeks, one (two weeks ago) was particularly bad, but Rita didn't go into hospital; she was treated at home. Rita isn't sure if she is prone to falls due to being unsteady on her feet due to the amputations or whether she is unstable due to her medication.

Since we last spoke, the doctor has visited her at home as well as the district nurse. Rita has been put on a drip for the cellulitis. She prefers to receive treatment at home. It is important that her dog is with her all the time. *"I'm getting better now"*.

Rita confirmed that her fire alarm was sorted on the very same day it started to sound nonstop - this was actioned by the PIC from Age UK. No-one has visited Rita from Age UK since, but this may be due to the fact that she has been unwell.

During our **interview at 91 days**, Rita reported she has been housebound due to ongoing illness since the last catch-up. Firstly, due to the cellulitis; a skin infection requiring a drip at home, which was regularly monitored by a nurse, and, secondly, a wound on her toes has opened, requiring visits from her GP twice weekly and the nurse to dress and drain the wound.

Rita has also had a further two or three falls over the past six weeks. The lifeline service was alerted each time and they came out to assist her back into bed. She hasn't gone into hospital for any of these falls.

Deteriorating health has prevented shopping trips with her carer and, apart from Age UK, she has rarely seen anybody else. While Rita has appreciated the visits at home from Age

UK and the friendly chats, she does miss going out. However, Age UK is largely restricted to doing home visits:

*"Well I'd like to go out but most of the people from Age UK, they don't have the facilities to take you out, their insurance on their cars, so they come here, which is very nice cos [name] who comes, she's been coming for a long time and we're friends now."*

Rita would prefer to continue to be cared for at home; the carers are providing a good service, as well as the dog walker, and the cleaner. However, due to the expense, the cleaning service has been reduced by one hour per week, and this means she can't have the rear of the house vacuumed. She admitted having to occasionally cut back on her food to pay for the carers, dog walker, and gardener. She also holds back on using her tumble dryer until it is really full and limits her use of heating:

*"I haven't got the heating on I tend to put a cardigan on or bring a blanket down to put round myself."*

Rita is keen to go out, to use the local hydrotherapy pool or go to the cinema, but the potential costs of these visits make them unfeasible:

*"The carer that would have to come with me and I can't afford to pay the extra for that. It would be nice perhaps to go out sometimes. Age UK do it, we used to go to the cinema. When I was walking a bit better, I used to go but now I can't, or if I do go, I'll have to pay for a taxi there and back."*

Whilst Age UK has made her aware of opportunities outside the home, she is unable to take them up due to the transport costs. Although the Age UK PIC has helped Rita access other services such as the Day Centre, the benefits of this were not felt as Rita didn't enjoy her time there. She is however, looking forward to attending a Christmas party in a few weeks. The social contact from Age UK is valued immensely. According to Rita this is an ongoing arrangement and she would "feel lost" because not only does she [the PIC] visit, but Rita knows that she can phone her if she needs to.

At the point of our **18/19 week catch-up**, Rita's health had deteriorated further; the wounds on her toes hadn't healed and she will be put on a drip again for cellulitis - *"it's worse now than it was before"*. The nurses continue to visit regularly to dress the wounds and change the intravenous drips - *"they're very good...I'm well looked after"*. She is bedridden and now lives upstairs 24/7. This change further isolates her from the outside world. Previously, she would be sat downstairs facing the window.

The arrangement with the dog walker and cleaner remains unchanged. The care package remains unchanged although recently there was some discussion about increasing the hours of support for Rita; currently, carers are still providing support four times daily for thirty minutes each time. However, each time they visit there is limited time to talk as they are usually busy with tasks such as preparing meals.

Rita had a couple of falls a few weeks ago, which weren't serious, so the ambulance service wasn't called out. She remained on the floor for about half an hour, waiting for one of her carers to arrive to help her up.

Rita revealed, *"I haven't been out at all"* since the previous interview at the beginning of November. *"Saturday and Sunday, I got quite depressed that was because I wasn't going out, everything seems to be going wrong"*. Age UK are no longer visiting, but she doesn't know why - *"nobody's been in touch...they just stopped coming and that's it"*. Rita explained that more than anything she misses social interaction. She is desperate *"to see somebody else as well"*.

The Christmas party that Rita was looking forward to attending now seems like an unrealistic prospect due to her illness.

During our **six month interview** Rita reported that although her health had improved considerably, i.e. the cellulitis had gone, yesterday she fell and cracked a rib. The fall resulted from unsteadiness due to her toe amputations. She didn't see her doctor until the following day, *"I didn't want to go to hospital"*. Rita was disappointed because she had planned to go out for lunch with her carer, after a long time being housebound. The doctor advised that she recover at home for a fortnight before attempting to go out.

Since an improvement in Rita's health she has tried to spend more time downstairs, *"I try to come down for lunch, I stay down because I was spending too much time you know upstairs in bed.....you feel more ill....so I get out [of bed], even try sitting in the chair, I feel better"*. She hasn't been in hospital; however, the nurse visits twice weekly to dress her wounds - *"it's not got any better, but it's not got any worse"*.

Rita recalled previous shopping trips (followed by lunch) travelling in the carer's wheelchair accessible car:

*"We'd go to the garden centre and then she [the carer] gets a wheelchair and pushes me and we go into the café there and they do some nice lunches, we done the shopping online this time."*

The carer's support is crucial for Rita to remain at home. Although there was some discussion about increasing the care package for Rita this did not materialise. Other assistance such as the cleaner and dog walker also remains unchanged. Age UK haven't been in contact, *"I just don't know [what's happening] ...I wish they'd come and discuss things, but they haven't been"*.

## Walter

Walter is 82 years old and lives alone in his own home. He has a number of health problems which affect his lungs, kidneys and heart. His health deteriorated when his mother passed away. He is permanently dependent on a portable oxygen concentrator and he uses a colostomy bag. Carers provide help with cleaning mainly, twice daily; morning and evening. Walter pays for this service privately.

*I "And the service that the carers provide, is it important to you?"*

*R It is yes, they clean up and Hoover the kitchen and put out the washing and everything. I do my own meals, I always have."*

Walter doesn't get out much as his wheelchair is very heavy and it is difficult for him to get in and out of it, especially with the oxygen device, but family members and friends living nearby provide frequent visits and help, for example, his sister-in-law does his shopping. Nevertheless, Walter's narrative reveals that he misses the outdoors, a change of scene and "a bit of fresh air".

Approximately ten weeks ago, Walter was admitted into hospital with blood pressure problems and he stayed there for six weeks. An Age UK PIC approached him during his stay and provided information about their PCD Pathfinder service. Walter expressed that he wanted to get out and about more often and was pleased that his request was met:

*"She came to me and seen me and told me what was what, and they took us out, we went one day, it was beautiful weather."*

The current care arrangements i.e. the carers service, is more than satisfactory, and, clearly, Walter values the social interaction he gains from the carers' visits on a regular basis.

*I "So what impact has that care had on your life?"*

*R Well it's very good to be looked after, they come in and talk to you and get on with the work and do everything and somebody coming in everyday, it's someone coming in."*

## Telephone catch - up six weeks later

The Age UK PIC visited Walter at home and talked to him about his needs. Since her visit, Social Services have also seen him to discuss whether he would like a befriender. Walter has joined the befriending service and is waiting to meet his befriender. Walter didn't realise that the PIC played a role in arranging the befriending. He is looking forward to "having a talk, have a cup of tea". He misses the company since his mother died.

Walter acknowledged that Age UK has helped in various ways: changed the times for the key safe installed in his home; requested mobile oxygen equipment with a shorter tube to prevent trips and falls.

Three or four weeks ago Walter decided that he didn't need help from a carer in the evenings, only in the mornings, so he changed this arrangement. The current situation is better for him, particularly as he is trying to maintain his independence.

Walter is due another visit from the PIC and then the Age UK service will be withdrawn. Walter doesn't feel he will miss them as he has good neighbours and family who regularly pop round and the befriending service will also provide him company. However, he recognised that the PIC had supported him a great deal, for example, she drove him to his GP surgery, which he couldn't do himself due to the oxygen canister that he carries. She has provided company and visits outdoors, which seem to be most valued.

### **Assistance from the Personal Independence Co-ordinator:**

- Referred into Age U.K. Lifeline while in hospital.
- Key safe installation organised with family.
- Contacted oxygen suppliers on discharge as new equipment and trip hazard with extra-long tubing- rectified the following day.
- Organised blister pack with GP on discharge as discharged with a lot of additional meds and confusing for patient, improve compliance.
- Collected meds from dispensary after 3 day delay with UTI being identified and delivery.
- Social trip out to the sea with elderly friend, 1st time using mobile oxygen, gaining confidence shared ice cream.
- Supported visit to GP with oxygen.
- Referral into befriending service.
- Visit to local group for tea and cake.

### **The Personal Independence Co-ordinator reported:**

Walter has been able to reduce his care package. He has had ongoing issues with his catheter but this is now being reinstated so that he can attend social activities. Walter is quite happy to be in his own home and is gaining confidence to use the mobile oxygen. He is now on a waiting list for a befriender but always welcomes opportunities to go out with his elderly neighbour who was also in hospital at the same time as himself.

### **Interview at 91 days**

Walter continues to draw on support from his network of family and friends; his sister-in-law and friends continue to visit, shop, and cook for him. The new arrangement with the carers is also working well. Having been on the waiting list of the befriending scheme (that the Age UK PIC put him in contact with) for some time, a lady came out to see him recently. He commented, *"she was here a couple of hours, very nice young lady"*, although, he wasn't able to clarify how often he will see her as part of the befriending arrangement.

The PIC visited him a few weeks ago, but she didn't discuss with him when her involvement was due to finish. Nevertheless, Walter is very appreciative of her help:

*"It was great cos she's a lovely person and we'd talk about different things, not your health and everything and we'd have a bit of a laugh, she's good fun, she's lovely."*

Her responsiveness to meeting his individual needs was valued - *"she'll help you with what you want done if it's possible"*. The PIC initially told Walter about the Day Centre, but his health problems restricted him to the home, which is why she then helped him to access the befriending scheme:

*"Day Centre, there's one down here I think too but I said no I don't want to, I'm happy here, cos I got all this water trouble and you've got to stop somewhere.....I said I'm alright, as long as somebody comes and visits me I'm happy."*

At the point of our **18/19 week catch-up**, Walter reported, *"I'm eating well, drinking well, and sleeping well"*, but will be seeing a specialist on 3<sup>rd</sup> January for the diagnosis of a medical condition because of considerable weight loss. His weight is monitored weekly as a result.

Luckily, he receives a lot of help from his neighbour and sister-in-law. Two different people from the befriending service have been visiting him at home over four or five weeks, *"they're*

*very nice, they are here for an hour or two". One befriender visits every week - "we have a bit of talk, I don't talk about my health, I just talk about....when we were younger in the war time....we have a good laugh in a way". He commented that it was nice that, "you get the same person every week". Walter looks forward to these visits and they are greatly valued, because he feels, "It takes the monotony out of things".*

The Age UK PIC worker is missed by Walter, he said, *"she'll do anything for you and is a good laugh"*, but he recognised that it would be some time before she returned to work.

He reported that the carers met his needs adequately - *"do what I ask them"*, but he did share that he was beginning to struggle to bathe himself, but didn't want to ask the carers to help - it's something he has always done himself. It is important to Walter to hold on to his independence.

During our **six month interview** Walter reported that he had seen a specialist and was referred for a scan before a follow-up appointment in February. Although he has continued to lose weight, he hasn't been feeling *"too bad...I'm eating and drinking, and sleeping well"*. The reduced care package has continued to work well for him - all of his care needs are met.

The same befriender visits weekly; her company is appreciated, *"it takes your mind off things and.....it's lovely, you forget yourself"*. Here, Walter was referring to the visit as taking his mind of his health problems. He recognised that seeing the befriender improved his wellbeing - *"I look forward to her visit.....it breaks the afternoon up sometimes"*. As long as the volunteer befriender is willing to visit, this should be an ongoing arrangement.

Although Age UK are no longer involved in Walter's care, he anticipates feeling the benefits of some of the changes his Age UK PIC initiated early on, for example, the safer portable oxygen equipment - he commented, *"in the summer, with a bit of luck, I can go out the front, sit down with a chair - the seat out there is lovely there, in a sunspot, so that will be very nice"*.

Apart from the one occasion, Walter hasn't been admitted to hospital as his health problems are well managed through the care and support he receives. Despite the Age UK PIC making him aware of the services available to him locally, he prefers to stay at home, especially as his family and friends visit regularly and provide him the company and support that he needs.

## Albert

Albert, aged 90, was identified by Age UK, through the ward round, when he was admitted to hospital with severe gout to both hands and feet. He had no formal statutory support prior to admission apart from primary care services. He admitted to having several falls and was struggling with continence and mobility.

Albert lives alone in a housing association bungalow. He has lived in the area all his life and previously worked the land. He has supportive neighbours who tend to the garden and one son who visits once a week to do the shopping. Prior to going into hospital, Albert did not have a formal care package. Albert was managing well at home, and was largely independent, until he developed gout in his feet.

While Albert was in hospital his PIC worker brought him a newspaper to read and keep up with current affairs (Albert had to stay in hospital for a prolonged period of time while awaiting a package of care and during this time felt isolated). The PIC worker helped Albert set up a package of care:

*“We had lots of conversations about what Albert wanted, the fact that he needed a bit of help with shopping and cleaning.”*

Albert was worried about his banking when he returned from hospital, so his PIC worker contacted his bank and ordered him a cheque book. They also managed to arrange for Albert to receive Attendance Allowance:

*“I think having that extra bit of money as well has been quite useful for Albert.”*

Although Albert didn't want to go out and socialise too much, his carer arranged for him to go on a visit to the seafront with his neighbour:

*“Albert wasn't wanting to go out and do lots of social things but the nice thing that happened is Albert and Walter have got the same carers and had messages going between them. When it was sunny when they first came out, they both said they hadn't been out for a long time, so we went out and had an ice cream down at the front and they reminisced about what happened in the war.”*

At the **six weeks catch-up point**, his PIC worker reported that Albert had continued to improve. The gout in his feet was healing and he was being well supported by carers. He had improved fluid and nutritional intake and his mobility had improved. He had another trip planned with his neighbour. Albert had not had any further hospital admissions.