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Integrated Care System
North East & North Cumbria

frailty
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YEAR OF CARE
PARTNERSHIPS

Implementing Proactive Care Using the Year of Care Approach to Personalised Care and Support Planning

Contents

Foreword

Over the last 22 years as a General Practitioner I have spent my time working mainly within the community setting, looking after those people most vulnerable, especially elderly people living with multiple conditions and frailty. I have also spent over a decade trying to explore new ways of delivering and commissioning services that are evidence-based and designed by people for people. It is all too clear that people want coordinated care, with continuity of relationships and time to talk, offering both preventative as well as responsive care close to home.

Although we are offering more advice, support, and care than ever before our services are saturated. The current health and care sector's growing demand for urgent care, coupled with resource and workforce challenges, mean that vulnerable people aren't supported to remain well and independent at home. It is critical now more than ever that we embrace and provide 'evidence-based' proactive, personalised advice, support, and care to those who are most vulnerable. Not all, but many solutions, to our saturated urgent and crisis care services lie in a targeted proactive care offer. It is this that will pre-empt and reduce the need for many future reactive care episodes and ultimately improve the experience and outcomes for all.

This proactive care pilot programme was funded to explore how the national Proactive Care Guidance (Dec 2023) could be adopted in Primary Care Networks by emerging Integrated Neighbourhood Teams (INTs). Led by the Year of Care team, this pilot was a feasibility study, trying to explore all aspects of the model (the what), and its adoption (the how) in the 'real world'. This was done using the Year of Care methodology and exemplified throughout by a case study - 'Eric' - a person's proactive care story.

This report offers valuable learning and insight based on a set of core principles for proactive care, including recommendations and resources that can support implementation. This forms the basis of a 'Proactive Care Toolkit' that will accompany this report and provide local places with a resource to begin or continue to build their existing proactive, personalised care model.

It has been an absolute pleasure to be a small part of this pilot programme and I want to finish by acknowledging the great work that all the professionals involved have achieved, with a special thanks to my Year of Care colleagues whose experience, skills and leadership have made this all possible.

Dr Dan Cowie
GP and Ageing Well Clinical Lead North East North Cumbria ICB

Summary

In 2019, the NHS Long Term plan set out a clear ambition to change the way we deliver healthcare; it emphasised the need for care to be more personalised, joined up and preventative. The more recent 'proactive care guidance' (2023) builds on this and supports a shift from reactive care to a more proactive way of working for a specific group of people; that is, those living with multiple long-term conditions and frailty.

Data suggests that this cohort of people are much more likely to experience care that is fragmented and focused on single issues. They are also at higher risk of needing urgent unplanned and emergency care. Not only does this increase the burden on our system, more importantly it impacts on patient's experiences and outcomes; influencing how they live in their final years, and how they die.

This report details a pilot programme which demonstrates that proactive care can be delivered successfully. It outlines a new model for implementing proactive care based on the well-established Year of Care approach to personalised care and support planning. The aims of the pilot were to place the patient at the centre of their care, so they had a greater sense of choice and control, to support them to live well for as long as possible and to reduce avoidable exacerbations of ill health.

This report follows the journey of two primary care networks in North Cumbria who worked hard to implement this approach in practice. It details how the process was developed, provides examples of supporting resources and emphasises the role of digital systems in identifying people and delivering high quality care.

The report findings show that the journey was not always an easy one. Learning from this pilot programme emphasises the importance of coherence amongst teams; knowing what it is you are trying to achieve and for whom at the outset. It also highlights the need to have the right resource to deliver what is essentially 'new work' with access to appropriate multidisciplinary team support with medical oversight. Knowledge and expertise around long-term conditions and frailty is also key. To help implementation, training and facilitation support is also recommended, alongside IT tools and access to the right digital systems.

This pilot explored the initial design and implementation of this approach; there is not yet any measure of impact however the staff reported many perceived benefits of working in this way. These include greater patient involvement, improved coordination of care, reduced treatment burden, enhanced ability to self-manage and improved access to preventative opportunities. This approach also offered the opportunity to have meaningful discussions about preferences and wishes that could form the basis for care both now and in the future. It was seen as a positive approach to working in a more proactive, personalised way.

Detailed information on this pilot programme including the process, lessons learned and recommendations for implementation can be found in the main report.

Chapter 1: Background

The health and social care system is facing unprecedented demand. An ageing population, widening health inequalities and the rise of those living with multiple long-term conditions are all placing an increased burden on an already overstretched system. To help reduce pressure on services and improve outcomes and experience for patients, it is recommended that people living with frailty and multiple long-term conditions receive care that is proactive, coordinated and planned, and offers the right support to help them to live well and stay independent for as long as possible.

This notion of 'proactive care' supports the ambitions of the NHS Long Term Plan and offers a shift from the traditional reactive, episodic care to an approach that is personalised, meaningful and considers a person's health and wellbeing not just in the context of their health, but within the context of their whole lives.

> *"Proactive care is personalised and co-ordinated multi-professional support and interventions for people living with complex needs."*
>
> **NHS England proactive care guidance 2023**

At the outset of our work a draft framework of proactive care (formerly known as anticipatory care) was being developed by NHS England to support the evolution of integrated neighbourhood teams. Whilst this guidance is now available[1] former iterations recommended earlier intervention for individuals living with multiple long-term conditions and frailty who are at risk of adverse health outcomes or reliance on unplanned care. This was to be delivered through a personalised, multidisciplinary approach to care comprising of six core components: case identification, holistic assessment, personalised care and support planning, multidisciplinary working, coordinated care and interventions and support.

Our programme was developed prior to the publication of the final NHSE proactive care guidance in Dec 23 and whilst some of the emphasis in guidance has changed, particularly in terms of frailty, our programme successfully delivers on all areas. This report will sometimes reflect models detailed in former iterations of the framework, however.

It is widely recognised that there are benefits from adopting a more proactive approach to care, yet research to support this remains relatively scarce. There are only a limited number of studies that have supported anticipatory or proactive care as an effective intervention in reducing hospital admissions[2] [3] and achieving cost savings for the health and social care system[4].

Taking a proactive approach has never been more important as we face a future where people are living longer and with more complex needs. Indeed, over the next 20 years the number of people living with multiple long-term conditions (MLTC) is expected to increase significantly. MLTC (including frailty)

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[1] https://www.england.nhs.uk/long-read/proactive-care-providing-care-and-support-for-people-living-at-home-with-moderate-or-severe-frailty/

[2] Leckcivilise, A, McNamee, P, Cooper, C, Steel, R (2021) Impact of an anticipatory care planning intervention on unscheduled acute hospital care using difference-in-difference analysis. BMJ Health Care Inform 2021 May;28(1):e100305

[3] Health Improvement Scotland (2022) Implementing Anticipatory Care Planning in Care Homes: Using quality improvement methodology to implement a new approach to anticipatory care planning in care homes. Accessed at https://ihub.scot/media/9422/20210607-acp-in-glasgow-care-homes-case-study-v10.pdf on 11th May 2023

[4] Brazil, K., Cardwell, C., Carter, G. et al. Anticipatory care planning for community-dwelling. BMC Geriatr 22, 452 (2022). https://doi.org/10.1186/s12877-022-03128-x

present a significant challenge to the NHS as they are a strong predictor of both routine and emergency care usage and a key driver of health and social care costs.

Across the North East and North Cumbria (NENC), early analysis[5] shows that there are around 574,000 people living with two or more long-term conditions, and of this number 8,800 are recorded as having five or more A&E attendances. 6,000 of the 574,000 living with MLTCs have also had a secondary care presentation for a condition that could have been managed out of the hospital setting. Those who are frail and aged over 65 are more likely to be admitted, making up approximately 47% of all hospital inpatients nationally[6]. These demands are only set to increase over the next twenty years as the ageing population grows[7].

Alongside the need to reduce hospital admissions, there is a strong moral and practical imperative to consider how to deliver proactive care for people living with MLTCs and frailty. People often report receiving care that is fragmented, task-focused and subsequently doesn't involve them as much as they would like in decision making or planning of their care[8]. This means individuals are unsure how to navigate services and manage their conditions confidently day to day or in an emergency. In addition, individuals may not have conversations about their future health or advanced preferences about where they die or have these recorded in a shareable manner within an accessible health care record. This is evident in the data with only 37% of those on a primary care register dying in their preferred place of death[9].

This pilot programme built on the moral imperative and existing research to determine a method to implement proactive care in practice.

Delivery of the pilot by Year of Care Partnerships

The Year of Care Partnerships team is based at Northumbria NHS Trust and has nationally recognised expertise in service design as well as the development and delivery of personalised care training and resources. Year of Care supports practitioners and teams nationally and internationally to develop the skills, processes and organisational change needed to embed personalised care and support planning (PCSP) as routine clinical care for people with long-term conditions and frailty.

The Year of Care model aims to deliver a personalised care experience increasing patient involvement, improving care coordination and supporting patients and their carers to manage their conditions in the community and thereby improving health outcomes, quality of life and reducing health inequalities.

This pilot programme aimed to test and spread PCSP to more individuals within the North East and North Cumbria focusing on ageing well, proactive care and frailty.

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[5] Information was provided by North East Commissioning Support in December 2022. Figures quoted for A&E attendance and secondary care admissions were for the previous 12 months.

[6] Doody P, Asamane EA, Aunger JA, et al (2022). The prevalence of frailty and pre-frailty among geriatric hospital inpatients and its association with economic prosperity and healthcare expenditure: A systematic review and meta-analysis of 467,779 geriatric hospital inpatients. Ageing Res Rev 80: 101666.

[7] North East & North Cumbria Frailty I-CARE Toolkit (2021), v16. Accessed 12th December 2023 at NENC-Draft-Frailty-Tool-V-30.8.18-003.docx-final-Sep-4th-version-002.pdf (frailtyicare.org.uk)

[8] https://www.health.org.uk/publications/understanding-the-health-care-needs-of-people-with-multiple-health-conditions
Health watch :"What People want from the next 10 years of the NHS"
Richmond group of charities One in Four: manifesto for people with multiple health conditions
https://richmondgroupofcharities.org.uk/sites/default/files/trg_one_in_four.pdf

[9] North East and North Cumbria Ageing Well Network (2023) Accessed at Our Opportunities « I-Care (frailtyicare.org.uk) on 16th June 2023

Year of Care acted as the lead organisation for coordination and support of this proactive care programme, working closely with the two Primary Care Networks (PCNs) and an overarching steering group. The Year of Care role was to provide expertise to enable the design, delivery and evaluation of the proactive care model.

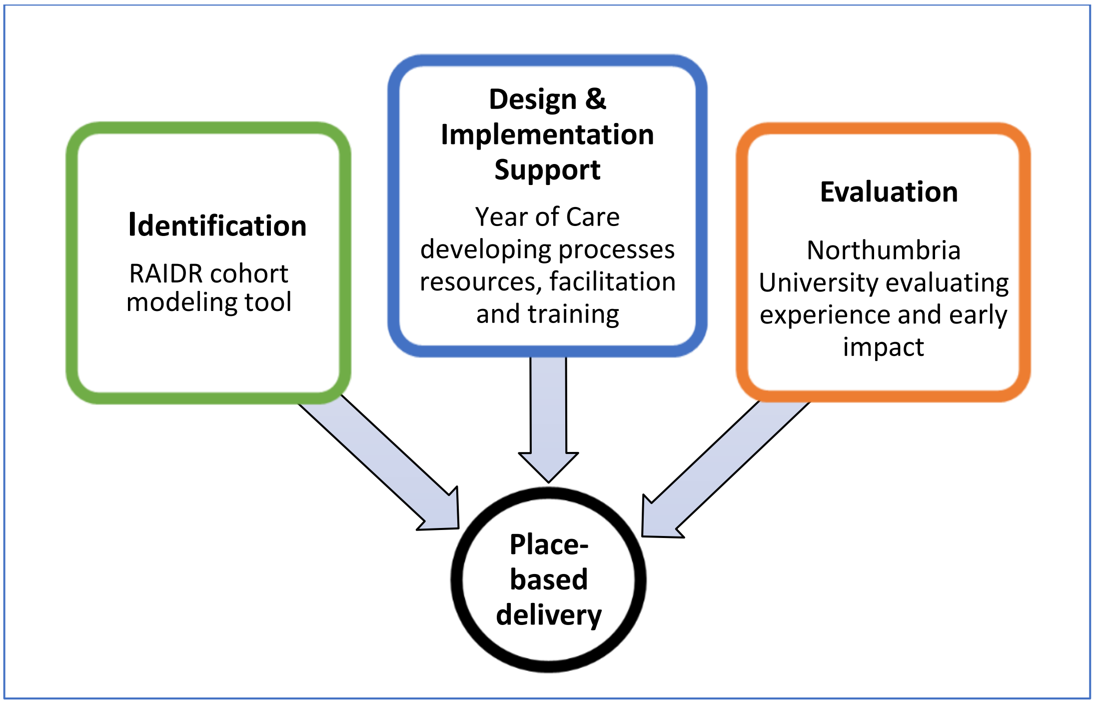
Activities included:

- Recruiting the PCNs and coordinating information flow throughout the programme
- Designing processes, patient resources and identifying workforce issues
- Identifying opportunities for digital development
- Ensuring cohesion between the regional Enhanced Care for Older People (EnCOP) competency framework and the proactive care programme development
- Identifying training needs amongst the PCN teams around older people and frailty relevant to the care pathway, including long-term condition management
- Delivering training on personalised care and support planning to staff delivering proactive care
- Supporting the development and review of resources including co-design workshops
- Setting up and managing an overarching steering group
- Developing and monitoring a delivery plan and timescales
- Event coordination for launch and review events alongside meetings and other activities
- Supporting the evaluation team with coordination and review activities

The above activity was led by the Year of Care National Director and our National Training and Facilitation team and coordinated by the Year of Care Business Development Manager.

Programme Aim

The overarching aim of this programme was to evaluate the feasibility of implementing a model of proactive care in primary care and community settings using the Year of Care approach to personalised care and support planning (PCSP). There were several elements of support which were included in the programme with different organisations leading on their development.



Programme Sites

During the programme we designed and tested a replicable approach to proactive care within two North Cumbria primary care networks (PCNs): Carlisle Healthcare and Keswick & Solway. Practice profiles and search data are available in Appendix 1.

Carlisle Healthcare PCN

Carlisle Healthcare is a single practice PCN serving a population of around 38,000. The PCN had been working with Year of Care to adopt a personalised care and support planning approach for people with long-term conditions (LTCs) for approximately ten years. During the last five years they expanded this approach to people living with moderate to severe frailty and multimorbidity through a dedicated 'home visiting' team. This was initially to support people with long-term conditions who were no longer able to attend primary care/GP practices for their usual personalised care and support planning review and by default were frail, but to also identify proactively those who would benefit from care coordination and were using unplanned care. The approach was initially funded by unfilled GP vacancies and was delivered by a small team of care coordinators and frailty nurses supported by a lead GP. A case study about the implementation of personalised care and support planning in Carlisle Healthcare PCN prior to this pilot programme can be accessed here.

Carlisle Healthcare PCN expressed interested in this pilot as their service had lost traction over recent years due to the COVID pandemic and dominance of urgent care, and a reduction in coherence with a rapidly expanding primary care team. This programme offered an opportunity to regain momentum and recreate coherence across the expanded team, and to standardise approaches, processes, documentation and information sharing. In addition participation allowed the PCN to share learning across the region and the wider North East North Cumbria ICS.

Keswick & Solway PCN

Keswick & Solway PCN and the Integrated Care Community (ICC) team had begun working closely together to establish a flagship joint employment model for a new Neighbourhood Anticipatory Care Team who would provide personalised proactive care.

They expressed interest in the proactive care pilot as they wanted to build on some local work around 'compassionate care' to support the personalisation agenda, and to provide a positive example of integrated working across primary care and community services.

Keswick & Solway PCN consists of seven GP practices, supporting a population of around 40,000. The aim of the new service was to provide personalised proactive care across the neighbourhood (PCN and ICC) in a way that was integrated and supported by multidisciplinary team working. The neighbourhood team was later named the 'Your Health Matters Team' and consisted of four care coordinators overseen by three occupational therapists, funded through the Additional Role Reimbursement Scheme (ARRS).

Governance

An overarching steering group was formed to oversee progress with members from the North East North Cumbria Integrated Care System (NENC ICS), Year of Care, Northumbria University evaluation team and the NHSE personalised care programme. Year of Care ensured the bi-monthly steering group meeting agenda raised pilot programme issues from the PCNs and invited PCN representatives to join the meetings.

Year of Care encouraged development of local steering groups within each PCN who met at regular intervals to address local issues, facilitated by the Year of Care team. Year of Care also supported learning and sharing between the PCNs at face-to-face events held locally in North Cumbria.

Programme Timeline

The programme began formally in April 2022 with an expected timeline of 12 months. As the programme developed it became clear that this timeline should be extended to allow for recruitment of team members in Keswick & Solway and the development of IT templates for data entry and documentation. The programme then ran from April 2022 – December 2023 however both PCNs will continue to provide the services beyond the end of the formal programme.

Evaluation

Formal evaluation of the programme was carried out by Northumbria University who appointed Prof Darren Flynn and Dr Debra Morgan to conduct an early service evaluation. The aim was to explore the views and experiences of staff from the PCNs involved in the organisation and delivery of the Personalised Anticipatory/Proactive Care Programme (using the Year of Care approach to PCSP) to capture learning around implementation issues and processes using Normalisation Process Theory (NPT).

An evaluation report (Appendix 2) was generated that considered data from both the surveys and workshops and the ‘implications’ of this. A summary of the findings can be found in Chapter 4.

The benefit of an evaluation process early in the programme timeline was that these early findings informed programme development.

Chapter 2: Methodology: How we developed and delivered the programme

The aim of this pilot programme was to develop a model of proactive care (formerly known as anticipatory care) based on the Year of Care approach to personalised care and support planning. There was national guidance on *what* 'proactive' care models should include however guidance or evidence on *how* to deliver this in practice was scarce.

The Year of Care approach provided an evidence-based structure that could form the scaffolding for a new model of proactive care. This programme was developed and delivered in collaboration with two primary care networks (PCNs) via a series of workshops and events alongside more targeted pieces of work to test the feasibility of implementing proactive care in primary care settings using the Year of Care approach.

Recruitment of PCNs

An expression of interest form was designed and shared across the NENC ICS area – it gave some details of the programme and outlined that PCNs interested in this offer would be asked to:

- Complete the expression of interest form with as much detail as possible
- Implement personalised anticipatory/proactive care at PCN level (agreement across the PCN required)
- Identify a clinical lead to join an operational group
- Ensure relevant professionals attended training on offer
- Participate in evaluation and learning activities

An introductory webinar was held in June 2022 for PCNs that had expressed interest in the programme followed by individual interviews, before two were selected to take part.

Programme launch events

In Oct/Nov 22 we delivered programme launch events for Keswick & Solway PCN and Carlisle Healthcare PCN who had been selected to take part in the pilot. The events were designed to bring together key partners and professionals with the key aims of:

- Networking
- Creating coherence around the programme - what we wanted to achieve, why personalised proactive care is important, programme governance and what we mean by anticipatory/proactive care and personalised care and support planning
- Beginning to consider how to identify the group of people to involve in anticipatory/proactive care
- Understanding the principles and processes of personalised care and support planning
- Beginning to consider training and development needs and how the programme could be evaluated

At the programme launch events (and throughout the programme) we used several case examples (including Eric - page 24) to help the teams better understand people's experience of the current systems and processes of care.

The sessions were well attended and successful in building enthusiasm and interest in the programme. They helped teams to understand the focus and purpose of the work, and the support available. Some key activities were identified during the events including refining the cohort of people to invite to the programme, developing processes and documentation, understanding staff training needs and establishing support required for implementation (see further detail in Appendix 3).

Process mapping sessions

Following the launch events, a series of process mapping sessions were completed with the individual PCNs. These sessions were attended by staff directly involved in the delivery of proactive care, with valuable insight from a patient representative at one of the sessions in Keswick & Solway.

The aim of the process mapping sessions was to explore and develop a care process based on the principles (see page 29) that were developed at the launch event alongside supporting resources and exploring enablers and barriers.

The sessions were framed around the Year of Care approach with consideration of the six components of proactive care (identification, holistic assessment, personalised care and support planning, multidisciplinary working, coordinated care and interventions and support).

Since Carlisle Healthcare had an established service model in place, these sessions were an opportunity to explore current processes and systems in relation to proposed changes to the care processes. This was then analysed and adapted to ensure it reflected the principles of the programme and the Year of Care approach, as well as integrating the six core components of proactive care.

This pathway was then used as a basis for process mapping and exploration within Keswick & Solway, who were new to this way of working. The mapping sessions focused on each stage of the process and enabled teams to learn throughout. Decisions were then made with close consideration for the patient experience, skill mix of the team, local infrastructure and support. Further details of the development and content of the care processes is in Chapter 5.

Focused pieces of work

During the process mapping sessions and development of the proactive care processes it became clear that there were some focused pieces of work required to support the delivery of this programme. These were:

- Development of the patient held care plan
- Creation of a new IT data entry template to support the process
- Developing an overarching ‘role outline’ for care coordinators to inform learning and development

Further details of these can be found in Chapters 3 and 5.

Sharing event

In March 2023, an event was held with both PCNs to share progress and learning, and to participate in evaluation workshops. Specifically, the aim of this session was to:

- Provide an opportunity for staff to share learning around progress and implementation.
- Enable staff to participate in local evaluation focus groups. These focus groups were led by researchers from Northumbria University and explored the views of staff members in relation to proactive care, its perceived benefits and feasibility in practice. The outcomes of this can be seen in Chapter 4.
- Provide an opportunity to collaborate on development of tools and templates for the purpose of standardisation across the PCNs.

Developing and delivering a training and facilitation programme

To support implementation, a training and facilitation programme was developed by the Year of Care team for staff involved in the delivery of proactive care within the PCNs. It was designed to reflect the principles of the programme and consisted of both formal and informal delivery.

Alongside the engagement events listed above Year of Care offered ongoing, advice, support and expertise around the programme. This mentorship approach consisted of regular meetings, ad hoc information sessions and online support. This was reinforced by a formal training course that was delivered by Year of Care over three half day sessions and was formulated around each stage of the new process of personalised proactive care. It was intended that this would help staff understand the purpose, tasks and communications skills associated with each stage of the process.

A case example (Eric – page 24) was used throughout the training sessions to help reinforce learning and support application to practice. The sessions were based on adult learning theory and were interactive, utilising activities, demonstrations and skills practice to support learning.

The three half day training sessions were delivered face to face in local venues in Cumbria. The sessions were attended by frontline staff, responsible for delivering or overseeing proactive care across both PCNs. There was an overall attendance rate of 93%. An overview of the training content can be seen below:

Session	Title	Key area for learning
1 3.5 hours	What do we mean by proactive personalised care?	• Understand the drivers for change and why proactive care matters. • Understand the underlying principles and process for delivering proactive care using a Year of Care approach. • Explore the philosophy, ethos and values which underpin a personalised care approach. • To consider how long-term conditions and medicines management are integrated into the care and support planning process
2 3.5 hours	Hearing the patient's story	• Understand the value and methods of 'preparing people' ahead of any care and support planning conversation • Understand how to use effective communication skills to build trust and rapport and gather information in a person centred way • Consider the structure and approach used for the information gathering/initial patient conversations • Understand the critical role of the multidisciplinary team in delivering proactive care and how that fits in the care and support planning process
3 3.5 hours	Planning with people	• Focus on the planning of care with people, including the structure and style of the complex conversation • Increase awareness of shared decision making - what it is/ what it isn't and how it links to proactive care • Explore and practice goal setting and action planning and how to construct a good care plan • Understand the importance of more than medicine for the proactive care group • Increase awareness of advanced care planning and how these fits into the proactive care process

Formal evaluation of training was completed at the end of the course. The feedback demonstrated that learning had taken place on a wide range of areas associated with the delivery of personalised proactive care, including emphasising the underpinning philosophy, recognising the value of preparation and how to have good practice care conversation with people. 100% of attendees reported they would recommend the course to others.

A copy of the full training evaluation summary can be seen in Appendix 4.

Chapter 3: Information Technology and Digital

The two key digital developments that were important to support programme delivery were

- testing and refining a newly developed digital search tool to proactively identify patients who met the criteria for the programme
- an integrated IT data entry template which supported the proactive care processes and the production of a care and support plan developed with the patient

Identification of patients

At the time of the programme launch there was a national focus on determining the population who could benefit from proactive care (anticipatory care); the recommended cohorts can be seen in Figure 1. There were certain groups excluded because they were included in other national programmes, for example care home residents covered by the Enhanced Health for Care Home framework.

Figure 1 *- National Proactive Care: Population in Focus (December 2022)*

1) Individuals with **2 or more LTCs** (one physical) including frailty from the following groups
2) **People living with moderate or severe frailty**, a population group likely to be predominantly but not exclusively older adults
3) **People relying on unplanned care** i.e., admissions to hospital and A&E attendance to manage their conditions
4) **People experiencing health inequalities,** defined as the top 20% most deprived populations and those within health inclusion groups

Exclusions:

- People with multiple mental health problem and no physical health problem
- People on specialist treatment plans e.g., Severe Mental health or End of Life
- Children and Young people under specialist services
- People living in care home covered by Enhanced Health in Care Homes Framework

The NENC ICS digital workstream had been working in collaboration with the Ageing Well workstream to develop a RAIDR case finding tool that would identify individuals who met the proactive care criteria and enable the extraction of patient level data for PCNs.

It was originally intended that the tool would be ready for use by March 2023, however this was delayed until June 2023. This delayed the PCNs in terms of understanding the size and complexity of the caseload and understanding the real needs of people in this group which impacted on workforce planning, implementation of the service and measuring impact.

To mitigate the delay in terms of development of care processes and associated tools, we used case studies based on the above criteria to help the teams understand the range of conditions, complexity and issues that people might be living with.

Once the RAIDR case finding tool was available, each PCN was required to have data sharing agreements signed by each practice manager to access the aggregate data. RAIDR identified NHS numbers which were then extracted from the tool and imported into local clinical systems to identify individual patients. This created additional work in practice and whilst the searches were useful in identifying individual patients who might benefit from the approach, practices then needed to review these lists to identify if individuals were already in receipt of planned care.

Testing the regional case finding tool

Initial scoping of the data identified by the RAIDR tool highlighted some challenges relating to its use (see search data in Appendix 1). These included:

Issues relating to coding at practice level/how individuals were identified

- Coding of frailty - the NHSE proactive care population identified those living with moderate or severe frailty as one of the key cohorts for intervention. Across the ICS it is recognised that many practices code frailty based on the electronic frailty index with no validation at individual patient level (using tools such as the Clinical Frailty Scale/Rockwood Score) and therefore this coding may be inaccurate. Carlise Healthcare had already addressed this issue but to help Keswick & Solway a Year of Care trainer and facilitator with expertise in frailty delivered a session at a PCN learning event in May 2023 on the use of the Clinical Frailty Scale (Rockwood score) as a means of validating frailty status. Over 30 staff members attended from both community teams and GP practices.
- Health inequalities data - the identification of health inequalities in clinical systems was done via postcode (geography) alone and this meant searches were inaccurate as they did not include other key factors such as socioeconomic status, specific characteristics (e.g. ethnicity, sexuality) and socially excluded groups (e.g., those who were homeless). This led Keswick & Solway to take the decision to exclude this group from their searches.

Issues relating to RAIDR tool exclusions

- Exclusion of care homes – both PCNs were looking to deliver this as an integrated service for people living with moderate/severe frailty, which included people living in care homes. They reported that exclusion of this group in searches felt artificial.
- Whilst mental health was not one of the search criteria, it was a concurrent and dominant issue for many people identified within the cohort, which impacted on the composition and skill mix of the multidisciplinary team (MDT).

Issues regarding usability of the RAIDR tool

- Both PCNs tested the RAIDR tool as a way of identifying individuals for proactive care. Carlisle Healthcare reported that the steps required to import and run the searches and generate the patient lists were time consuming. They opted to run real time searches via PRIMIS or identify their cohort via local intelligence instead. This may need consideration in any future roll out and choice over how this is done should be considered.

A team from NENC ICS worked to address the issue of frailty coding by developing a new method in EMIS Web and SystmOne to support the eFI; this was made available to the PCNs towards the end of this pilot programme in Dec 2023. This method has greater specificity and sensitivity in identifying people living with moderate or severe frailty based on some clear identified criteria, as seen in Figure 2.

This method will require practices to set up their own searches in clinical systems based on this method; validation using the Rockwood scale will still be required.

***Figure 2** - Case finding moderate/severe frailty on EMIS Web/SystmOne – July 2023*

***Step 1** - search clinical systems*

Over 65 and any of the following:

a. Palliative care
b. Care homes
c. Housebound
d. Dementia
e. 90+ years of age
f. Calculated eFI is in the severe range

***Step 2** – clinical verification of frailty status*

Use PRISMA score and/or Rockwood Clinical Frailty Score to verify frailty status.

***Step 3** – patient record*

Apply appropriate SNOMED code to identify frailty in individual patient record.

Using 'local Intelligence' to refine the cohort

Each PCN used local intelligence to augment the RAIDR searches to identify people for the proactive care service (and excluded people they felt weren't appropriate). Clinicians added individuals to the proactive care service following post-discharge meetings and morning huddles, and identified those who were high users of primary care services within existing processes and systems.

Carlisle Healthcare PCN

The team had been delivering personalised care and support planning for housebound patients for many years and therefore had well established means of identifying individuals for the service. This involved placing patients on a manual register, rather than coding and searching through the EMIS Web system. This cohort included:

- People with long-term conditions who were no longer able to attend the surgery for review (housebound and usually frail)
- Those on the list for planned annual long-term condition review who ceased to engage with the practice
- Those identified by MDT discussion/contact with practice staff including those reliant on unplanned care
- Hospital discharges (triaged for appropriateness)
- Moderately or severely frail (clinically validated)
- People aged over 80 who were not known to practice (proactive contact as an offer)
- Care homes - managed by a separate team, working in an overlapping role

During process mapping sessions with Year of Care, issues were identified relating to this local cohort. One key factor was that the search tool identified a 'new' cohort of people who were not housebound and so would be excluded from the existing service. The existing caseload was large, had not been reviewed for some time and there were concerns about the ad-hoc way staff referred or identified people for the service. To address these issues it was agreed that the existing caseload would be reviewed for appropriateness and the case finding tool used to support cohort identification.

The searches identified a significant number of patients who were not known to the home visiting team (may be attending planned care in the practice) but may have been appropriate for proactive care however due to staffing, programme timeline and resource shortage this was not explored during the term of the pilot programme.

Keswick & Solway PCN

The team felt that the national criteria for proactive care and the supporting regional RAIDR tool may identify large numbers of people for the service. They decided that local intelligence would be valuable and identified the following groups as being in scope:

- Frailty, particularly those in the moderate or severe category
- Care home admissions
- Hospital discharges (triaged for appropriateness)
- Those living with multiple long-term conditions and frailty who have experienced a high number of emergency admissions
- High users of unplanned care at practice level
- Those identified by practice staff or other MDT members - a forum for this existed in the practice in the form of morning 'huddles'
- Those living with long-term conditions and not engaged with the practice

To manage demand, the team initially focused on those who were identified as high users of services within one GP practice in the PCN footprint. This was predominantly driven by the opportunity to start small and offered a manageable caseload to train staff and to test and embed processes. However, it quickly became apparent that some of these patients were already known to other services offering personalised care and support planning, e.g. mental health, or required professional input outside of the remit of occupational therapy. It was therefore agreed to shift the focus to frailty and the team felt that focusing on those with living with mild or moderate frailty who were accessing unplanned care would beneficial. This aligns well to the new proactive care guidance published in Dec 2023 which supports the wider case finding approach e.g. high level of primary care and/or urgent care use.

Once people were identified as suitable for the programme PCNs were asked to apply the national SNOMED codes for anticipatory/proactive care in the electronic patient record as listed in Appendix 5.

Creating a new data entry template

To support the delivery of the proactive care process, an IT data entry template was required to facilitate the process, and this became a key focus of development for the programme. The design of the template needed to support the documentation of both the information that was gathered (assessments) and the care and support plans developed with and by the individual. By default, we needed to be clear about the patient cohort (what was needed clinically) and the process (what would be done when and by whom) ahead of developing this. Our aim was to ensure the template facilitated rather than dominated the process and that it was comprehensive in terms of high-quality clinical care.

We reviewed the potential clinical needs of people living with long-term conditions and frailty based on our existing Year of Care long-term condition work, the comprehensive geriatric assessment (CGA) and existing templates used in Morecambe Bay and North Cumbria.

We worked closely with the Cumbria Primary Care Information Services (PRIMIS) team, specifically Carol McTurk and Caroline Huntingford, together with representatives from both PCNs to design and develop the proactive care templates for information gathering and personalised care and support planning in EMIS Web.

We mapped the potential domains across the personalised care and support planning process as outlined below and worked with the PCNs to review and refine the potential template fields. The template includes several tabs which map to the personalised care and support planning process and has now been fully tested and published (Appendix 6). The fields in the template have also been reviewed against the Professional Records Standards Body (PRSB) core information standard.

Invitation and explanation about the programme (contact with care coordinator about the service)

- Demographics
- Social information

Information gathering visit (HCA/care coordinator)

- Carers and services
- Capacity and consent
- Physical tests and assessments
- Functional ability

Personalised care and support planning conversation

- Care plans (including)
    - What's important to me and what I want others to know about me
    - Professional summaries
    - Self-management plans
    - Emergency care plans
- Future care decisions
- Advanced care plan documents

The above fields were refined via PDSA cycles during early use by individuals from both PCNs. SNOMED codes were used in the template which were common to the regional dataset and those recommended by NHSE for both proactive care and personalised care and support planning (Appendix 5).

Chapter 4: Staff views on value, purpose and delivery

A mixed methods evaluation was completed early in the pilot programme to determine staff views and experiences of proactive care, including the benefits and challenges, how they understood their role and contribution, and how the overall process worked in practice.

All staff involved in the organisation and delivery of the proactive care programme were invited to complete an anonymous survey via the Qualtrics platform. The survey consisted of the 23 item Normalisation MeAsure Development (NoMAD) questionnaire (based on Normalisation Process Theory (NPT)). The aim was to collect data on implementation processes from the perspective of those directly involved.

Following survey completion all staff were invited to attend face-to-face interactive group workshops where, supported with appropriate information from the aggregated analysis of the NoMAD questionnaire, staff perceptions were further explored around key implementation issues. The workshops were held with the individual PCNs and facilitated by researchers from Northumbria University.

The responses from both the questionnaire and focus groups were analysed using NPT to establish identification of relevant themes. These are summarised below, and the full evaluation report is in Appendix 2.

Coherence and purpose

Coherence and clarity of purpose across a team is an important part of the initial implementation of any new way of working to ensure teams stay on track with the work they do and are clear about the issues they are trying to tackle and outcomes they're trying to achieve. During this pilot programme Year of Care delivered launch events and in-practice facilitation to support this outcome.

The evaluation identified a strong sense of coherence and purpose around proactive personalised care; the staff recognised that it is a positive way of working with many benefits for both patients and practices. Their views demonstrated a strong commitment from the PCNs to work in this way, regardless of national policy, with staff supporting an approach that is planned and forward focused rather than acute and reactive.

"More proactive and preventative care hopefully reducing the number of unplanned visits to hospital and to the GP practices, this will allow teams to be prepared and patients to have the confidence that they have a care plan which is tangible"

There was also clear agreement that this should be delivered in a way that is person centred and focused on the individual to achieve the best outcomes.

"Listening to the patients' needs, not just being driven by their medical needs but a complete holistic assessment. Patients should then feel valued, empowered and unscheduled GP visits/ hospital admissions should be reduced"

Whilst there was a strong sense of common purpose and ethos there appeared to be a lower level of coherence around 'who' this approach was best for and 'how' it might be delivered.

There were also concerns that new team members or those in the wider MDT might not always understand the purpose of this work and drive a culture that is transactional and reactive rather than personalised and proactive.

Views on the extent to which the PAC programme offers a different way of working

The evaluation demonstrated a good level of awareness of this as a different way of working in terms of spending time with patients and actively engaging them in a conversation about their life, how they manage, what's happening, and what's important to them, including provision of supported self-management to help patients fulfil their goals and change their health behaviour.

This way of working was considered more than simply making assessments and documents more personalised:

"Instead of going in with a bit of paper and a load of questions, going, "right, I need to get through these, 'cos it's a tick-box exercise", is actually sitting with the patient and having a conversation about their life, how they manage, what's going on and what is important to them, so there's no point helping to change something if that's not what the patient wants to do"

"More person centred, using the patient's goals to enable them to gain knowledge and understanding of their own conditions and how to help themselves"

There was also recognition that supporting patients to be prepared was a crucial element of this work.

"Well, you know yourself, if somebody turns up at your door for an hour's visit and you weren't expecting them, once you've left, they'll think of a thousand questions, whereas if you've prepared them for what you're going in for, the questions are already thought of, so can be dealt with during the visit"

There was also broad agreement that a new personalised proactive care approach would enable time to work with patients to anticipate their future care needs, and to develop appropriate plans that addressed what matters to patients. **This was described as a a 'massive shift' from the current way of working.**

Benefits to patients

Staff were able to identify many benefits for patients which align well with the principles and purpose of the pilot programme and demonstrated coherence at a high level around the aims. This included being more holistic, personalised and preventative. It also recognised the value of engaging people differently so that they felt heard, more involved and in control of their health.

"Listening to the patients' needs, not just being driven by their medical needs but a complete holistic assessment. Patients should then feel valued, empowered and unscheduled GP visits/ hospital admissions should be reduced"

Staff also recognised practical benefits such as having more time and being able to see patients in their own homes.

"That's the good thing about like, seeing them in the home environment as well; you can see other things that you wouldn't necessarily see if they just came into the surgery and what other factors around them might be affecting them as well"

There was clear recognition of the benefits of this preventative approach in reducing treatment burden for both planned and unplanned care.

"Having a look into this approach and working, it should potentially prevent hospital admissions, or at least keep people closer to home, when they do get into these crisis situations, they've got a plan in place as to who to contact first, rather than just dialing that 999…. rather than just feeling out of control"

Within Carlisle Healthcare, there was also a strong sense that long-term condition management should form part of this approach to reduce treatment burden for patients, delays in care and hospital admissions. Other specific benefits identified were:

- Developing a therapeutic alliance
- People knowing what to do in a crisis or emergency
- Access to wider multidisciplinary team support
- Social prescribing and self-management
- Potential for avoiding unplanned visits to primary and secondary care
- Identifying and broadening the cohort of people who are involved

Coordination of care

Care coordination is an important outcome of personalised care and support planning for people with multiple long-term conditions, frailty and complexity since they are often seen by many professionals across a variety of organisations as part of their total care, which increases overall treatment burden. In Keswick & Solway the role of the care coordinator was seen as critical to delivering this aspect of the programme, including being a named contact and advocate for the patient.

"If they've got a lot of long-term conditions, they've just got loads of individuals going in and out all the time and not really being able to keep track on what's going on, so the care coordinator will be kind of their point of contact"

In Carlisle Healthcare, care coordination was considered as a function of the process, rather than as the role of a single member of staff. This was facilitated in several ways including having multidisciplinary team meetings and huddles to share professional expertise, combining all aspects of the person's care within the personalised care and support planning process, and having a single known point of contact within the community hub. This function was achieved by teams who may be co-located working alongside each other and sharing of expertise and experience.

Patient awareness of the proactive care process

Patients for this programme are identified from practice registers and are offered support proactively before needing to ask for it. Both PCNs recognised that this approach differed from how people currently accessed services, and it was important to consider how to engage people with the process and the clinicians who delivered it. Teams identified that this was something that needed to be done using interpersonal skills to build trust and rapport with the individual and not something that could be done solely via a letter or text. It was important to support patients to understand the potential benefits and ways of working of the PAC programme. It was also important to express that this was an ongoing service (in that people wouldn't be 'discharged' from it) and that support would be dependent on the needs and wishes of the individual.

Multidisciplinary teams (MDTs)

Staff viewed the multidisciplinary team as being critical to delivering proactive care; consequently, both PCNs employed additional staff to deliver proactive care. It was acknowledged that proactive care needs to be separated, in terms of staffing resource, from the acute reactive work which had the potential to take priority.

The broader emphasis on personalised care and support planning facilitated a transition from a purely medical model to a biopsychosocial model, which brought an understanding that people engaged in the programme are living with complexity and highlighted the need for teams to have access to a wide range of expertise (other professionals, services and third sector organisations).

"Well we have daily huddles as well, and MDT meetings, and once a week, professionals out of the surgery or the ICC come in, adult social care and the community mental health team as well, and again, it's another opportunity to see who's going to be best placed to go and see that patient and get updates of what's happened with that patient, isn't it?"

The role of the medical practitioner

There was recognition from both PCNs that GPs have ultimate accountability for clinical aspects of care, but also an acknowledgement that this would be delegated to the team who are responsible for their own actions as professionals. The role of the medical practitioner is seen as pivotal to this way of working in terms of both holding and sharing risk due to the complexity of the patient group.

It was recognised that GPs should supervise and support staff, provide medical oversight (e.g., test results, medication, diagnosis and prognosis) and where appropriate stand down redundant medical/clinical activity whilst not usually seeing the patient themselves. It was also recognised that patients would feel more confident in the service if they knew it was anchored to the primary care team and was a method of getting a view from a medical practitioner.

"In that whole governance and responsibility, the general practitioner maintains overall clinical responsibility for the patient in terms of chatting about medical things, and so the GP practice maintains overall responsibility for viewing any results, actioning them and receiving concerns in a timely manner. So if a care coordinator has been out to see someone and is concerned about their, medical condition, in the same way that a district nurse might do, or anybody going out to see a patient, then the responsibility is on the general practitioner to make sure that they're accessible and responsive in a timely manner and take appropriate action, I suppose"

There was concern raised about potentially adding to the burden of already high GP workloads where GP support hadn't already been identified as a component of proactive care. To create support for the proactive care team it was deemed important to raise their profile and promote the benefits of working in this way.

"It goes back down to the comms, doesn't it. We need to communicate it the best way possible, to show that this team is of benefit to you in the long run, so there will be work that will be generated by it. But you're going to have to suck that up because the rewards will come down the line when the triage list is not as high

The purpose of the care plan

Staff said that taking part in this pilot programme had led them to really think about the purpose of the care plan and who it is for.

In Carlisle Healthcare the care plan document had previously been considered a vehicle to convey information about the patient in an emergency to the ambulance and out of hours services. In addition, there was a section of the care plan which summarised 'what normal looks like' that had been helpful for practice team members during acute visits, at times preventing treatment escalation and admission. Whilst recognising that it was important that this function remained, this programme also led the PCNs to consider the value of the document for the individual patient.

> *"I guess my first thought is that it's for the patient and it's for them to hold and erm, feel control over, such that the contents of it reflect exactly who they are and what their wishes are and what their aspirations are, so primarily, it's for them and for them to have that record of being heard and listened to and that we've written down"*

The additional elements that the teams felt were required on the care plan were focused on patient needs including understanding what's important to the patient, 'self-help' (knowing what to do when they become unwell), their goals and how they want to live their lives and manage their health. There was recognition that some focus was needed on long-term condition management and maintaining function for professionals, whilst enhancing the self-management and daily living aspects for the patient.

The care plan was designed to be printed and left with the patient in their home, and teams felt that in future this should be shared digitally, particularly for sharing patient goals and preferences and emergency care details.

Training needs

Alongside the introductory session and support the teams recognised the need to understand each other's roles, which in part would be achieved by working alongside each other. Other training needs that were identified were:

- Long-term conditions – general training (including co-morbidities and complexity)
- Frailty including the comprehensive geriatric assessment and the use of Rockwood Frailty Scale
- Identifying red flags and signs of deterioration and knowing what to do or where to go
- Person centred communication skills (personalised care and support planning)
- Coaching and behaviour change approaches
- Awareness of local organisations (e.g., social prescribing and third sector) that could support aspects of proactive care
- IT systems, coding and templates

The teams subsequently highlighted the need for support with serious conversations about advanced care planning.

IT systems and documentation

One of the key enablers identified by the teams was a high-quality IT data entry template and patient centred preparation and care planning documents. The teams noted that these tools needed to support the programme and would make it easier to deliver, however raised concerns these can be used in a 'tick box' manner, rather than supporting a good quality conversation with the patient.

Generally, a single shared IT data entry template was seen as a key enabler to record assessments and care plans, avoid duplication, and sharing with a range of health and social care professionals.

Summary of independent evaluation

This independent evaluation highlighted a strong consensus amongst team members about the importance and value of proactive care as an approach for people living with multiple long-term conditions and frailty. Teams recognised this required a team approach, prioritisation within a busy health system and medical oversight to provide accountability and handle risk and complexity. It was deemed important to ensure any new team members understood the purpose and value of this way of working and how it differs from usual approaches to unplanned and/or reactive care.

Chapter 5: Developing a care process to deliver personalised proactive care

To develop the proactive care model and maintain its focus on person centred care we used clinical vignettes to engage clinical teams with the issues faced by people in the proactive care group and the care and support needs they have, including the healthcare burden that they must navigate. This was exemplified by Eric and his care experience as described below.

In this chapter we include:

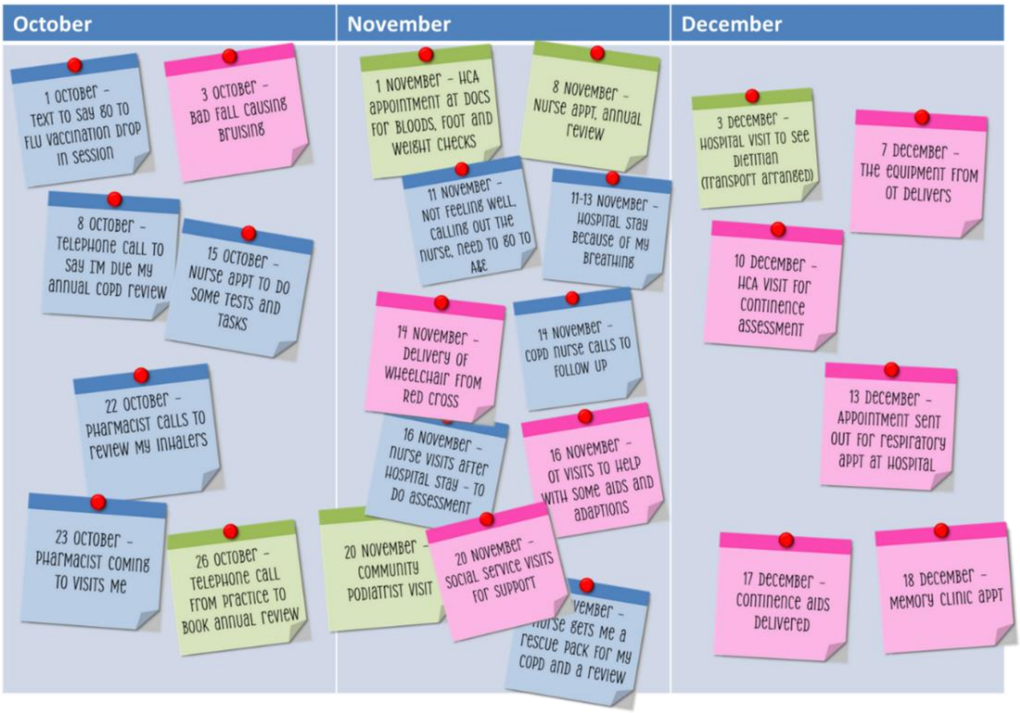
- **Eric's care without proactive care**
- **The principles we agreed were important when developing the proactive care process**
- **The proactive care process, and how it works for Eric**
- **How the PCNs implemented this**

Healthcare without proactive care

Case study - Eric

Eric is 84 and lives alone in sheltered housing. He has mild dementia, high blood pressure, type 2 diabetes, COPD and has been hospitalised 5 times in the past year. He suffers from back pain and has had 3 falls in the last 2 months. He is widowed but has a supportive friend who visits regularly; his daughter also lives nearby.

Eric is still largely independent but is finding his memory is becoming more of a problem; he doesn't always take his medications correctly and is finding functional tasks more difficult.



Prior to being invited to have his care coordinated via the proactive care programme over a 3-month period and following a hospital admission Eric has:

- 24 separate contacts
- 13 assessments
- contact with 20 different professionals
- referrals made to several services

The next 12 months without proactive care

The impact of receiving fragmented and task based care which isn't focused on planning is that Eric's needs aren't met, and his health deteriorates.

Diabetes

- No longer attending screening
- Difficulty managing medications
- High blood glucose levels
- Recurrent UTI's/nocturia
- Associated delirium

COPD

- Regular community reviews
- Finds it difficult to remember how to use rescue pack
- Exacerbations lead to hospital admissions
- Muscle loss impacts on breathlessness

Function

- Reduced confidence - no longer goes out, spending more time in his chair
- Deteriorating memory
- Increased pain
- Not managing medication well
- High number of falls
- Low mood

Impact

- Functional decline
- Hospital admissions
- More professionals involved
- Carer burden
- Psychological impact

The last years of life without proactive care

As Eric approaches the last few years of his life he has no advanced plans, he is at high risk of admission and healthcare professionals are unaware of his choices and preferences about his care.

- Eric is living in a care home - a best interest decision made by the state as he had no Lasting Power of Attorney (LPA) in place. He wasn't allocated to his home of choice, which impacts on his mood and quality of life.
- He has recurrent falls and infections and associated delirium with numerous hospital attendances (as he has no Emergency Healthcare Plan (EHCP) in place).
- He is resuscitated when unwell as he does not have an up to date DNACPR and eventually dies in A&E.

Principles of the personalised proactive care pilot programme

Using Eric's current experience of care, we worked with the PCNs to develop a set of 'principles' that staff felt were core to how we wanted to work and what we wanted to achieve.

Principles of the proactive care programme

1. Proactive and preventative; working in a way that supports people to live well for as long as possible and to anticipate future needs.
2. Care should be coordinated and ongoing. People should not receive 'episodes' of care that involve them being on or off a caseload. They should be known to the team and supported based on need.
3. Care should be personalised and individual; focused on what matters to them and what can make a difference to their lives, rather than what a service "usually" provides.
4. Assessment should be separated from conversations. Often, assessments are dominated by multiple questions and tests and leave little time for the person to express their thoughts, wishes and worries. Separating out data collection from the personalised care and support planning conversation ensures the patients voice is heard.
5. Meaningful conversations should happen with prepared patients. Patients should be encouraged and supported to think about what matters to them not just in the context of their health, but in the context of their whole lives. This is integral to the personalised care and support planning process
6. The approach should be holistic; considering all aspects of a person's life that may impact on their health, including aspects such as medical, functional, social, spiritual and psychological wellbeing
7. Context: recognising other members of the household and community support. It is important to understand a person's life story and the support networks they have around them. This creates a more personalised approach and helps to determine strengths and assets as well as needs.
8. Supporting people to live and die well, alongside self-management. Proactive personalised care is not just about asking people what matters to them and enabling access to social prescribing opportunities; it is about helping people to live as well as possible for as long as possible, reducing the risk of unnecessary admissions and providing choice and control as they approach end of life.

Things to avoid in proactive care

1. Just ticking a box; completing assessments because it is the accepted way of working.
2. Reactive care; responding to acute crises through short episodes of care rather than anticipating needs.
3. Completing multiple assessments by different professionals where information or expertise could have been shared to prevent overloading the person.
4. Duplication: each professional having a different assessment template that results in a person being asked the same thing multiple times
5. MDT making decisions for patients; patients should be involved in decisions about their care and have the opportunity to have their voice heard.
6. Taking over, creating dependency; patients should be encouraged to manage their own health and care needs, as much as possible, with the right level of support.

Developing a proactive care model

The principles above were used alongside the clinical vignettes as reference points throughout the pilot programme and during training to maintain focus and emphasis on the person.

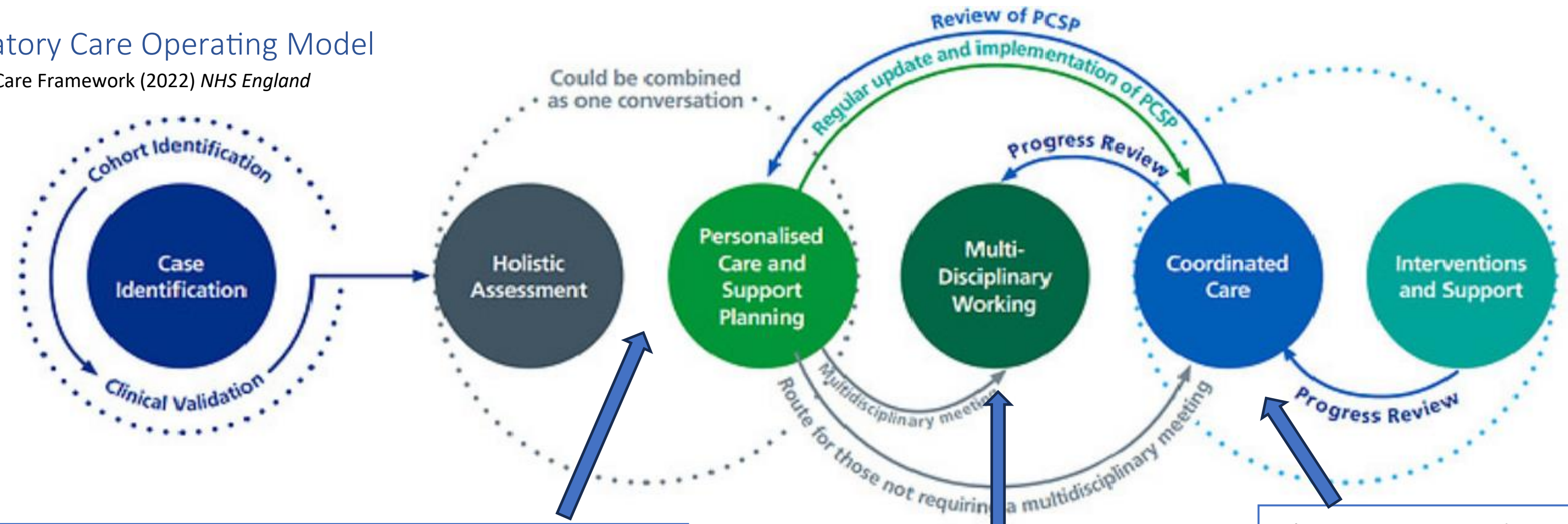
The core components of the NHS Anticipatory Care Operating Model from the draft anticipatory care framework are considered essential to the delivery of proactive care, however the draft framework did not outline how these components should be delivered and how they should be 'assembled'.

Please find the Anticipatory Care Operating Model on the next page together with some commentary from Year of Care.

Our approach was to work with PCN delivery teams to create an integrated delivery model for proactive care using the Year of Care approach to personalised care and support planning, focusing on the both the principles we developed and the components within the Anticipatory Care Operating Model below.

The Anticipatory Care Operating Model

Draft Anticipatory Care Framework (2022) *NHS England*



The holistic assessment and personalised care and support planning conversation should be done separately rather than combined as one conversation because:

- The holistic assessment, which could include a range of physical tests and assessments, has potential to dominate the process, taking time away from a proactive planning conversation.
- Separating these activities out allows time for review of assessment/test results/medication by the MDT in the context of understanding the patient concern and this helps identify which professional might have the personalised care and support planning conversation.
- The proactive care and support planning conversation can then focus on looking forward, informed by the assessments and options generated by the MDT, but with the patient in control of the decisions made and able to express their views about their future.

Most people who are identified as part of the proactive care cohort live with complex issues. Therefore:

- multidisciplinary expertise is required to support the individual team members who have care and support planning conversations to ensure people are supported to live with these issues.
- MDT review would be beneficial before the PCSP conversation to ensure this informs the planning process and important clinical issues aren’t missed.

The process provides care coordination throughout rather than as a one-off event at the end of the process.

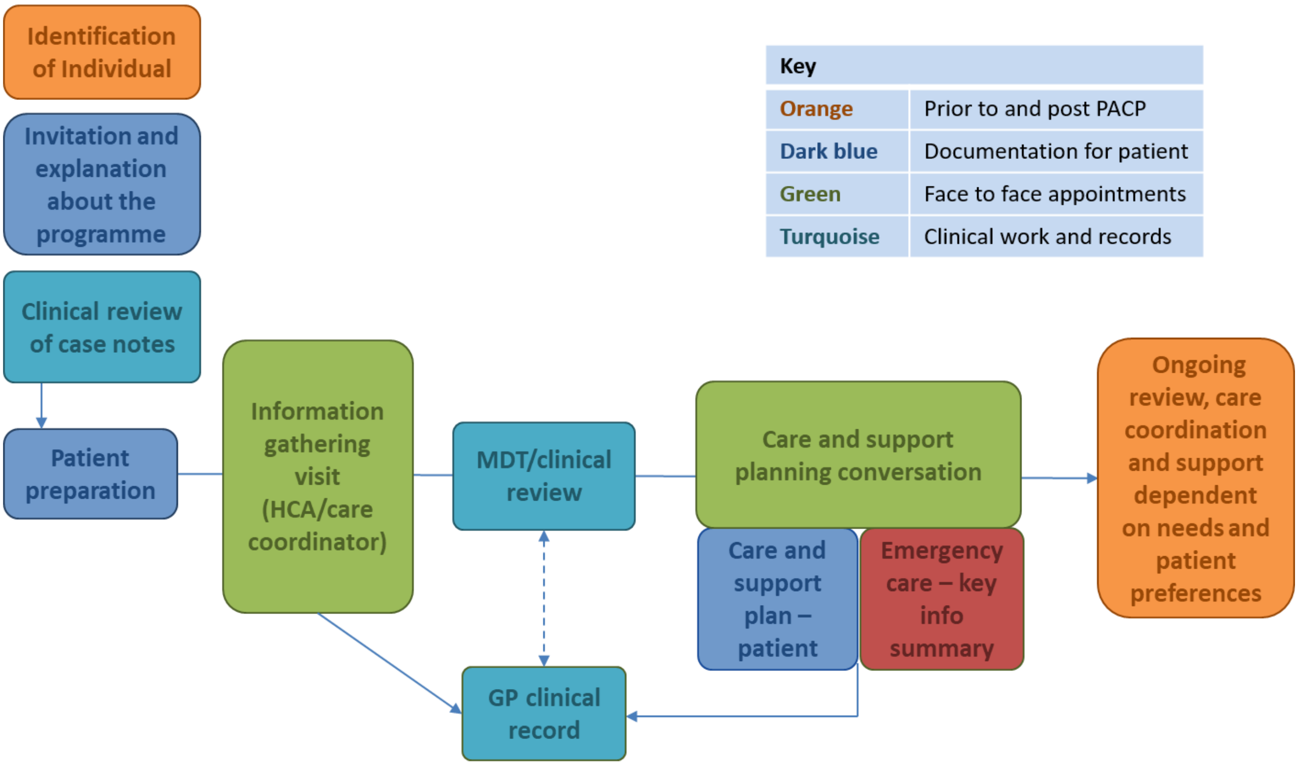
Coordination of the assessments into a single process for all long term conditions people live with leads to:

- Reduction in the number of separate visits by different professionals via extended roles and MDT support.
- Focusing on the things that matter to the person and that will make a difference clinically.
- Ensuring future planning and preferences are known to avoid unwanted medical intervention.

Using the Year of Care approach to develop a proactive care planning process

The care process for proactive care, developed with the PCNs, can be seen in Figure 3 and is described in more detail in this chapter. It consists of eight core steps, with two face to face contacts for the patient, designed to coordinate care and ensure greater patient involvement, meaningful conversations and the documentation of individual plans and future preferences about care.

***Figure 3** – The personalised proactive care process*



Key	
Orange	Prior to and post PACP
Dark blue	Documentation for patient
Green	Face to face appointments
Turquoise	Clinical work and records

What difference does this make to Eric?

This means Eric has fewer separate reviews and he works with a small group of professionals who get to know him well. He feels understood and has the chance to talk about what matters to him and he makes all the decisions about his care including being able to get support to stay at home, having choice and control over any future care decisions and being able to state his preferences about where he would like to be cared for in his last few days of life. He is supported to get out, keep in touch with social networks, and with issues like getting more sleep and being steadier on his feet.

Eric's GP practice support him to reduce his polypharmacy and understand better how to manage exacerbations. He is secure in the knowledge that all his health issues are being reviewed by a healthcare team working with his GP practice and knows who he should contact if he is unclear about his healthcare provision.

Eric's personalised proactive care process is depicted in figure 4.

Figure 4 *- The personalised proactive care process for Eric*

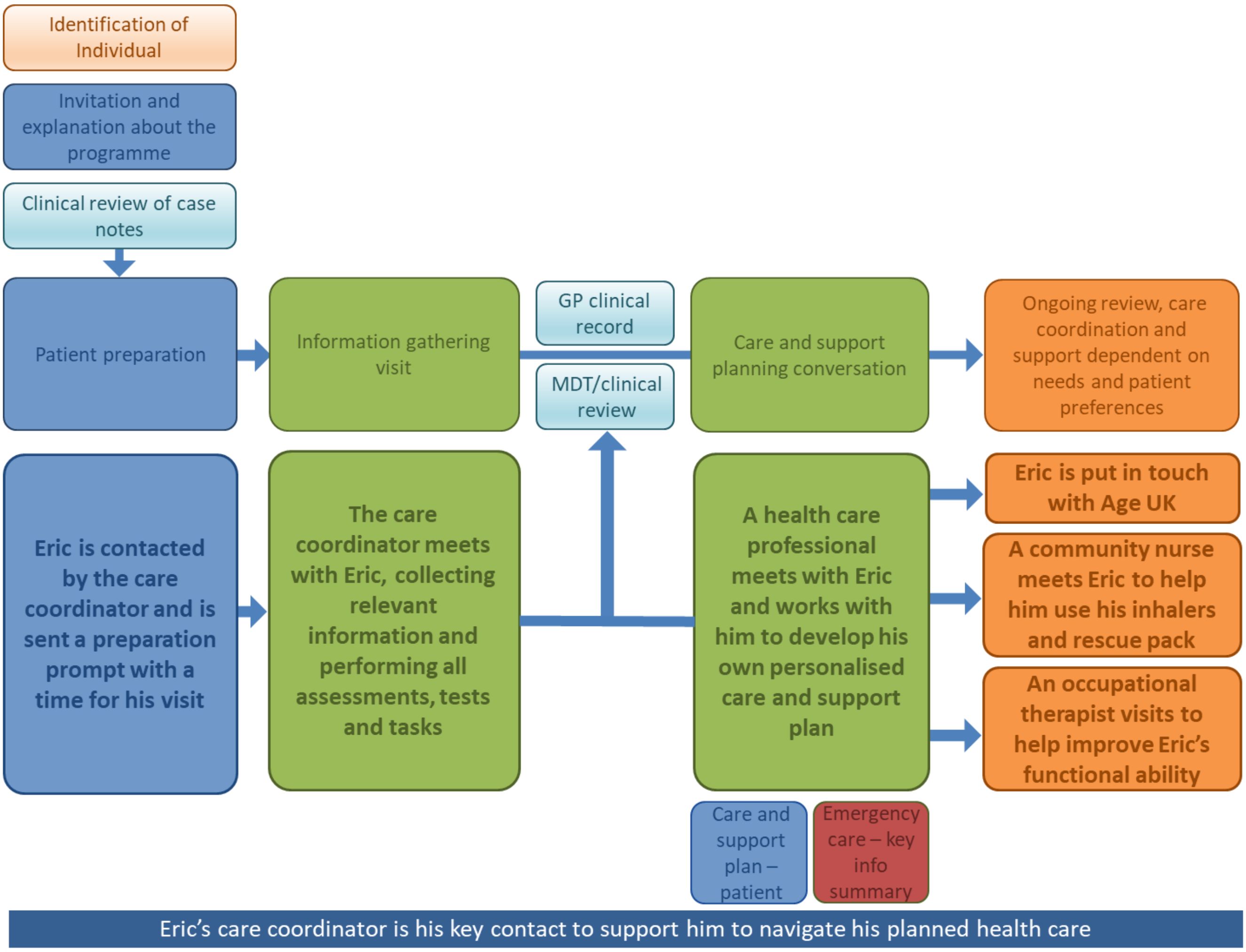
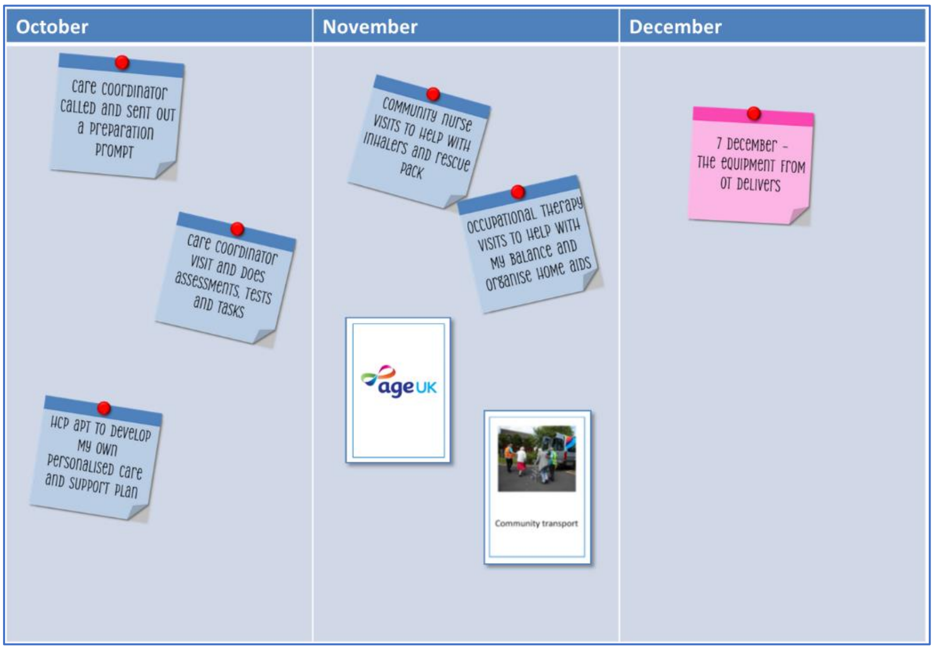


Figure 5 *– Eric's calendar with personalised proactive care*



Eric now has

- 8 separate contacts
- 1 holistic assessment
- Contact with 4 different professionals (with access to practical support from third sector organisations)

How the proactive care process works

Following the identification of individuals (as described in Chapter 3), patients such as Eric are invited to participate in the process as outlined in Figure 3. The detail of each of these stages is explored in more detail below.

Each stage is laid out in the following order:

- **The purpose of each stage and how it works**
- **What this means for Eric**
- **How this works in the programme PCNs**

Invitation and explanation about the programme

Invitation and explanation about the programme

People identified for proactive care from the clinical system and by anticipatory care teams may not understand why they have been selected to receive this service or be welcoming of this kind of support. The purpose of thinking through how to invite people to and explain the programme was seen as important in that it:

- Helps individuals understand the support offer and how it might help or be of benefit to them.
- Helps individuals understand what would happen and how the care and support would work.
- Helps people see the connection of the MDT and service to their own GP practice.
- Gives people the opportunity to take part in or decline the service and involve carers, friends and relatives to the degree they want.

There was agreement across both PCNs on the best way to invite people to the programme. This involved people:

- receiving an initial letter explaining the purpose and role of the service (Appendix 7), alongside appropriate promotional information with details of the team and clear links to the GP practice.
- This would then be followed up with a telephone call from an allocated care coordinator to provide more detail on the service, gain consent, provide the option to opt out and, if appropriate, arrange an appointment for an information gathering visit. To support staff completing the initial phone call, a 'Finding the Words' document (Appendix 8) was created during training sessions to help staff consider their language and to support clear and consistent messaging.
- Keswick & Solway decided that people would be allocated to care coordinators as part of the identification process during practice huddles.

What this means for Eric

Eric receives an initial phone call from a dedicated care coordinator who introduces themself and confirms they are linked to his GP practice. The care coordinator would tell Eric:

- He has been identified as someone who might benefit from the service which offers the opportunity to explore how things are going with his health and identify what could make a difference to him.
- It's an opportunity for the team to listen to his concerns and to consider what's important and matters to him most.
- The team provide support to coordinate his care and make sure nothing gets missed.
- Information about the service will be sent to Eric to help him prepare for the appointment, he is encouraged to read and complete it before the first visit.

Clinical review of case notes

Clinical review of case notes

The aim of the clinical review of case notes is to identify if any tests, assessments or checks are needed to provide safe and effective care. Reviewing case notes identifies tests required as part of long-term condition reviews, for drug monitoring or those related to other clinical concerns, such as recurrent falls or UTIs. This is an opportunity to identify any professional concerns, ‘red flags’ within the clinical record or share informal knowledge of the patient. This supports the information gathering process and ensures completeness of information being returned to the MDT for initial review.

Clinical review of case notes for Eric

Prior to the information gathering visit the care coordinator, with support from the proactive care team, reviews the clinical system to understand Eric’s relevant history and medications, and to identify any flags for missing information linked to QOF and LTC management.

Long-term conditions

Diabetes (type 2)
COPD
Dementia & frailty
5 hospital admissions in the last 12 months due to COPD/falls
Moderate frailty (eFI)

Medicines

Metformin mg – 1g twice daily
Atorvastatin - 20mg
Perindopril - 8mg once daily
Frusemide - 40mg once daily
Bisoprolol - 5mg once daily
Amitriptyline - 40mg at night
Salbutamol PRN (inhaler)
Duoresp Spiromax (inhaler) - one puff twice daily
Paracetamol 1g four times daily

Results recorded

Pulse – 78
O2 sats - 95%
CAT score 18 – scores poorly on sleep and feeling breathless and slowed down by it

Results not recorded at all/within last 6 months

BP
Rockwood score
HbA1c
Cholesterol/lipid profile
TFT and LFT
Weight
BMI
Foot screening (diabetes)
Retinal screening (diabetes)

Eric is assured that a member of the healthcare team is reviewing his clinical record and ensuring that any outstanding tests, tasks and assessments are completed as part of the process. This will reduce the need for separate assessments and will ensure that safe and effective decisions are made as part of personalised care and support planning, based on the sharing of up to date information, an understanding of his overall medical history and his most recent episodes of hospital care.

How clinical review of case notes works in the programme PCNs

In **Carlisle Healthcare,** clinical review of case notes was carried out jointly by the care coordinator and frailty nurse who are both experienced in this process and worked alongside other members of the clinical MDT as part of their initial induction. They reviewed the clinical notes in the GP system, noted any flags and considered additional tests as appropriate. Formal medicine review was not included at this stage, but outstanding blood tests for drug monitoring were picked up by an alert on the clinical system.

In **Keswick & Solway,** the team predominantly consists of occupational therapists and care coordinators who are new to the role. There is no allocated nursing time to support clinical review of case notes and there were concerns about creating more demand for local GPs. It was therefore agreed that the care coordinator would review the notes on the clinical system to identify any flags or actions relating to long-term condition management and the Quality and Outcomes Framework (QOF) and determine if any action was required. If there were outstanding alerts, they would be discussed with the practice team via tasks on the electronic patient record to determine the most appropriate course of action.

Patient preparation

Patient preparation

Patient preparation is a key element of personalised care and support planning. The aim of preparation is to ensure the person understands the offer of care and how things will be done, and that they have time to consider things and gather their own thoughts about their health and care and what matters to them.

Traditionally this is done in between the information gathering appointment and the personalised care and support planning conversation. For proactive care however moving this to the beginning of the process was more beneficial as it:

- Supported people to identify their own priorities, concerns and questions ahead of the personalised care and support planning process, making it easier to ensure all decisions are guided by the patient’s preferences and what matters to them.
- Replaced lengthy assessment tools with self-reflection tools that map to the domains of the assessment, giving the patient time to think things through and have more control over the discussion during the initial information gathering review.
- Gives the opportunity for families, friends and carers to be able to share their thoughts and concerns where appropriate.

For people living with multiple long-term conditions and frailty there may be lots going on in their lives; having the opportunity to prepare helps them to have a greater sense of control and gives permission to raise issues that they might not have previously including their concerns, wishes and needs.

Various preparation materials were explored with the PCNs, and it was agreed that the Year of Care preparation documents previously developed with service users would be selected. These would be shared with individuals in advance of their information gathering appointment by administrative teams.

The preparation material included two combined documents (Appendix 7):

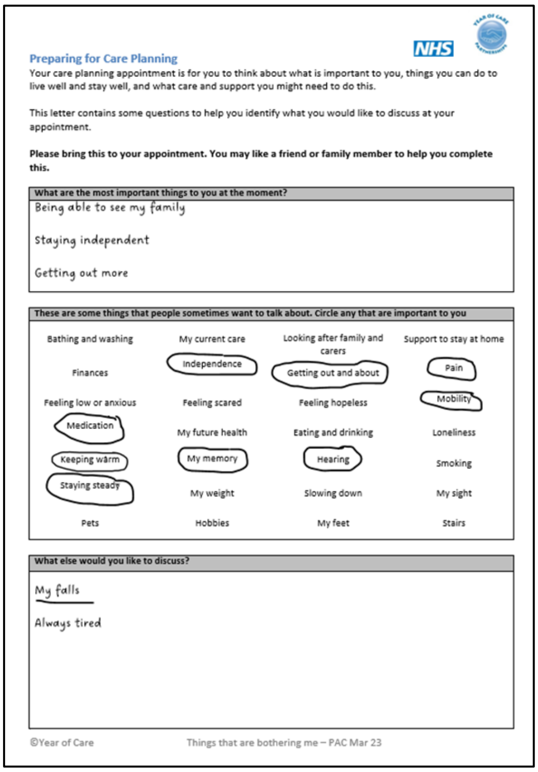
1. A generic ‘agenda setting prompt’ that helps people identify issues they want to discuss including topics such as getting out, medication and loneliness, with some free space to record what is most important to people and the questions or concerns they wish to raise during the PCSP conversation. This would be sent in the post with the invitation to the programme.
2. A ‘Things that are bothering me’ self-reflection tool that reduces the burden of assessment and encompasses many aspects of a person’s life such as physical health, functional ability, home environment, support network and psychological wellbeing. The care coordinator could assist

with the completion of the document when necessary and use it to support a narrative based assessment. The aim of this is to avoid the person feeling overwhelmed with endless questions that are not relevant or useful. This tool includes most of the components of a comprehensive geriatric assessment.

Learning from the programme highlighted the need to stagger this element of personalised care and support planning preparation, with the generic sheet being used before the initial information gathering visit and the ‘Things that are bothering me’ self- reflection tool being introduced as part of this visit, instead of using a healthcare professional checklist.

What preparation looks like for Eric

Eric can identity the things that matter to him ahead of the care and support process, so that he has time to think and feels he has permission to talk about the things that might make a difference to him. He understands what the service involves, and he can include his daughter Fiona if he wishes.



Preparing for Care Planning

Your care planning appointment is for you to think about what is important to you, things you can do to live well and stay well, and what care and support you might need to do this.

This letter contains some questions to help you identify what you would like to discuss at your appointment.

Please bring this to your appointment. You may like a friend or family member to help you complete this.

What are the most important things to you at the moment?

Being able to see my family

Staying independent

Getting out more

These are some things that people sometimes want to talk about. Circle any that are important to you

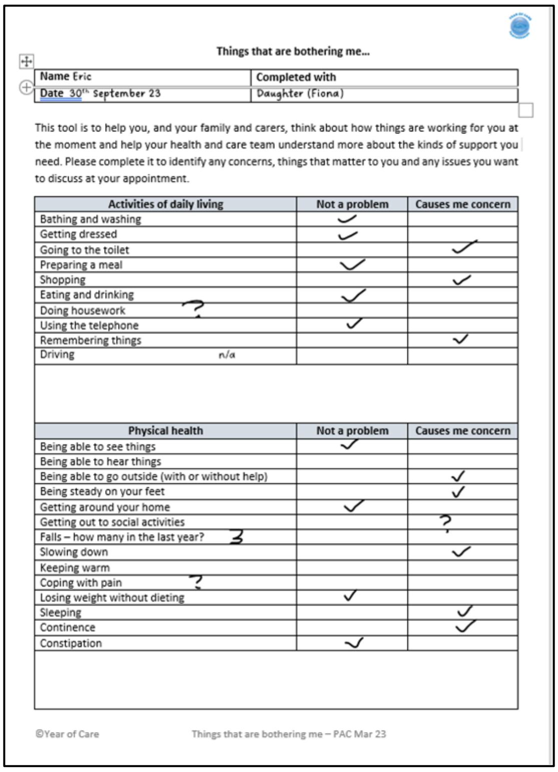
Bathing and washing	My current care	Looking after family and carers	Support to stay at home
Finances	[✓ Independence]	[✓ Getting out and about]	[✓ Pain]
Feeling low or anxious	Feeling scared	Feeling hopeless	[✓ Mobility]
[✓ Medication]	My future health	Eating and drinking	Loneliness
[✓ Keeping warm]	[✓ My memory]	[✓ Hearing]	Smoking
[✓ Staying steady]	My weight	Slowing down	My sight
Pets	Hobbies	My feet	Stairs

What else would you like to discuss?

My falls

Always tired

©Year of Care Things that are bothering me – PAC Mar 23



Things that are bothering me…

Name Eric	**Completed with**
Date 30th September 23	Daughter (Fiona)

This tool is to help you, and your family and carers, think about how things are working for you at the moment and help your health and care team understand more about the kinds of support you need. Please complete it to identify any concerns, things that matter to you and any issues you want to discuss at your appointment.

Activities of daily living	Not a problem	Causes me concern
Bathing and washing	✓	
Getting dressed	✓	
Going to the toilet		✓
Preparing a meal	✓	
Shopping		✓
Eating and drinking	✓	
Doing housework ?		
Using the telephone	✓	
Remembering things		✓
Driving n/a		

Physical health	Not a problem	Causes me concern
Being able to see things	✓	
Being able to hear things		
Being able to go outside (with or without help)		✓
Being steady on your feet		✓
Getting around your home	✓	
Getting out to social activities		?
Falls – how many in the last year? 3		
Slowing down		✓
Keeping warm		
Coping with pain ?		
Losing weight without dieting	✓	
Sleeping		✓
Continence		✓
Constipation	✓	

©Year of Care Things that are bothering me – PAC Mar 23

Information gathering visit (starting the conversation)

There are three key functions of the information gathering step in the personalised proactive care process.

1. An opportunity to get to know and understand the individual and develop a trusting, meaningful relationship, including identifying patient concerns and priorities to inform the rest of the process and identifying the most appropriate professional for the personalised care and support planning conversation.

Information gathering visit (HCA/care coordinator)

2. Information gathering is also a valuable part of holistic assessment as it enables the care coordinator to learn more about a person's life story and establish their strengths and challenges in the context of understanding what is important to them.
3. Ensure that all relevant assessments, tasks and tests associated with the person's combination of long-term conditions (QOF) and frailty (CGA) are completed so that all important medical, psychosocial and functional issues are covered. This includes information about physical health (blood pressure readings, height and weight, phlebotomy and foot checks) alongside mental health, functional ability, support networks, psychological wellbeing and completion of the Clinical Frailty Scale (Rockwood) to verify frailty status where appropriate.

Using a narrative rather than template driven approach to gather information was considered essential to the delivery of personalised proactive care. To facilitate this approach we:

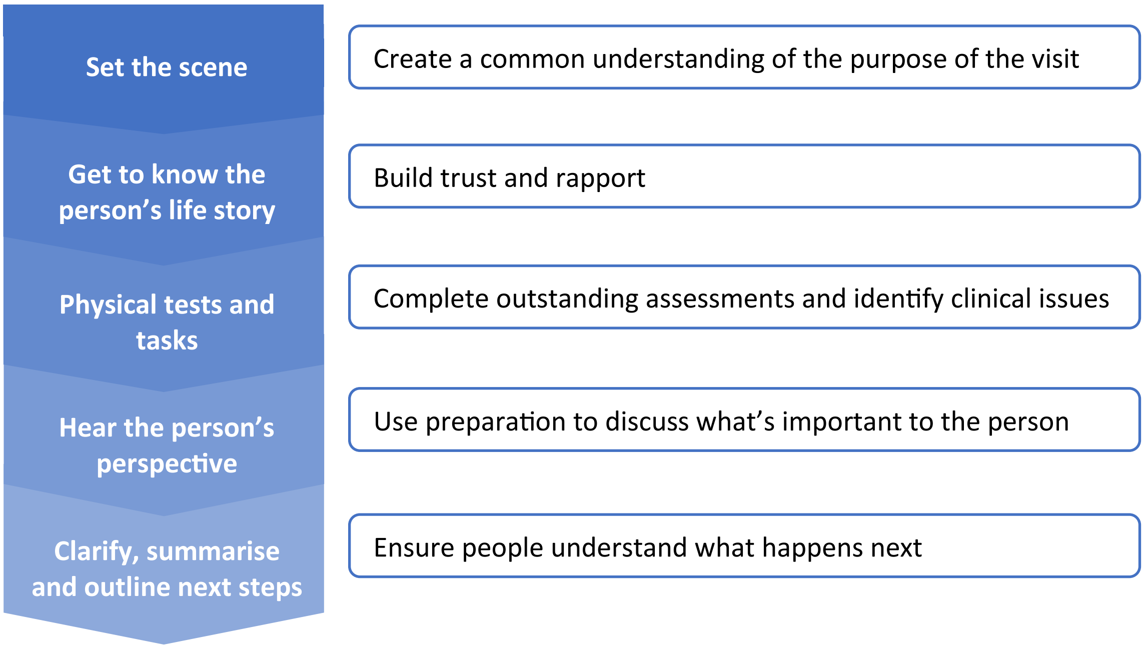
- developed preparation materials (as detailed above) that supported the person to identify what matters to them, so they could more easily voice their concerns during the information gathering process and subsequent personalised care and support planning conversations.
- Included this element in training for staff on personalised care and support planning conversations which focused on understanding the individual and listening to 'their story'.
- Worked together with the programme sites to ensure the IT template allowed ease of data entry rather than determining the flow of the conversation.
- Ensured the IT template offered space to create a key information summary including what's important to the patient and what they would like people to know about them.

Information should be collected in a conversational way using the preparation materials and effective communication skills. This step should involve family members and friends if requested by the person and may be completed over more than one visit where appropriate. This visit could also provide an opportunity to introduce relevant elements of 'Deciding Right' in advance of the personalised care and support planning conversation.

We agreed that a role outline for care coordinators would be developed with the PCNs for guidance on the required knowledge and skills of people in this role (Appendix 9). Ideas were collated from analysis of the existing care coordinator role in Carlisle Healthcare, the new personalised proactive care process and relevant competency frameworks such as Enhancing Care for Older People (EnCOP).

Figure 6 shows the structure of the information gathering conversation which seeks to balance the assessment aspects of this part of the process against getting to know the person and understand their concerns and issues.

***Figure 6** – Structure of the information gathering conversation*



Information gathering for Eric

Eric feels he can talk about the things that are bothering him and identify his main concerns and worries. He feels assured that all the tasks, tests and assessments needed to monitor his medication and conditions are completed at a single review and will be recorded in his electronic care record. If he chooses, he can have a friend or relative with him at this review and he has the chance to identify what he wants to discuss and any questions he has as part of his own personal preparation for the visit. He feels heard, valued, and trusts the care coordinator, who explains the next part of the process to him at the end of the review.

What we learn about Eric

Strengths
- Family and friends support
- Enjoys socialising and staying active
- Determined/motivated

Vulnerabilities
- LTCs - COPD not well managed
- Recurrent falls
- Memory
- Lives alone

What's bothering Eric
- Finances
- Sleep
- Continence
- Memory
- Medication/COPD rescue pack
- Getting out/seeing his family

What's bothering HCPs
- High risk of admission - falls and COPD
- Lack of heating
- Sleep
- Memory
- Medication

How information gathering works in the programme PCNs

Information gathering is well established in **Carlisle Healthcare** and is undertaken by a care coordinator who is NHS agenda for change band 3. The person has a high level of competence and knowledge around long-term conditions, frailty and has attended Year of Care training in personalised care.

Prior to the information gathering visit, the care coordinator reviews the clinical record and liaises with the frailty nurse to determine which tests and tasks are required for clinical or QOF requirements. The care coordinator completes the required tasks and informally follows an EMIS Web template during the information gathering visit to collect all the required information. The experience of the care coordinator enables this process to be conversational and focused on the person rather than the template or tasks.

There was concern that the EMIS Web template currently being used needed an update since it did not flow well, many sections were left incomplete, and it was unclear whether sections should be completed during the information gathering visit or following the personalised care and support planning conversation. The template also didn't link to other templates used by professionals in the team such as the occupational therapists and therefore questions were often duplicated. Reviewing the template was considered essential for this team.

This step was discussed in detail with the **Keswick & Solway** team. We explored the role of the care coordinator in proactive care and there was agreement that this involved getting to know the person and completing elements of the information gathering template. However, there were concerns from the Keswick & Solway team about supervision, governance and collection of some of the clinical information as part of this stage in the process, such as phlebotomy and foot checks. The care coordinator posts were newly developed and aligned to the occupational therapy team within community services due to the source of funding for their recruitment. Long-term condition management was not considered part of the role of care coordinators prior to recruitment.

In keeping with the principles of the programme our aim was to streamline care, reduce duplication and improve MDT working and therefore Keswick & Solway decided that the care coordinator would act as a conduit between the person and the practice in relation to management of their LTCs. The care coordinator would monitor whether reviews had taken place and encourage attendance, liaising with and supporting practices, however accountability and responsibility for LTC management would remain with the practice.

This approach reduced the amount of information that would be collated during information gathering and potentially also resulted in additional appointments for the person to attend. There was also a risk that a full clinical picture and all clinical issues were not being considered when planning care with people. To mitigate for this Keswick & Solway decided that the care coordinators would be joined by an occupational therapist until they gained experience and that the care coordinator role may be expanded in future.

MDT and clinical review

Multidisciplinary team (MDT) working and clinical review are important aspects of proactive care to ensure clinical accountability, safe and effective care and to provide guidance and advice on the array of issues that people who live with complexity, frailty and long-term conditions might present with.

MDT/clinical review

The proactive care framework identifies MDT support as a core component and aligns with national drivers towards integrated community teams. Having access to a multidisciplinary that may include doctors and nurses with specialism in frailty and multimorbidity, AHPs and mental health support is important for the proactive care team.

In our process there is a planned MDT review following the information gathering visit by the care coordinator. The key aims of this part of the process are to:

- Share the information gathered (results and assessments) and learn about the patient issues identified by the care coordinator.
- Review the results of any tests and assessments completed.
- Share the expertise of different professionals and identify any clinical or functional concerns and any potential options for these, ahead of the personalised care and support planning conversation.
- Agree which professional will have the personalised care and support planning conversation (based on continuity and the issues identified).

As we designed our process, we recognised that there needed to be an MDT review with medical oversight to support the team with risk and uncertainty, as well as specific issues such as clinical prioritisation and the management of clinical conditions and medicines, and coordination of support that people might be receiving.

In addition, we recognised that clinician input would be important so that:

- issues around polypharmacy and medication reviews could be incorporated into the proactive care and support planning conversation following review of the information gathered (e.g., anticholinergic burden for those experiencing falls).
- Individual team members would be supported around understanding the prognosis of individual patients and being clear about which aspects of medical care were important to attend to.
- Clinicians continue to ‘hold risk’ and ultimate clinical accountability for care.
- Advanced care plans could be completed by doctors or nurses who have had the training required training for this role.

What this means for Eric

The MDT reviews all the information that is collated as part of the information gathering visits and ensures that any clinical red flags are noted. The do not make any specific decisions about Eric's care but do generate some ideas and suggestions around potential options based on the clinical review and an understanding of what matters to Eric.

Test results

- HbA1c – 85
- Cholesterol 3.5
- TFT and LFT normal
- Weight 75 kg (some weight loss), BMI 28
- BP lying 156/92, standing 128/69
- Pulse – 78
- Foot sensation diminished
- Not attended retinal screening
- Rockwood score – 5 (mild frailty)
- O2 sats - 95%
- CAT score 18 – scores poorly on sleep and feeling breathless and slowed down by it

Professional concerns

- Diabetes (type 2) - HbA1c is 85mmol/mol
- COPD – breathlessness and sleep
- Dementia – forgetting medicines/safety
- Frailty – falls risk, deteriorating function
- Medication review (polypharmacy – falls and sleep)
- BP (postural drop)
- Eyes/feet

Desktop medication review

Falls

- Review Furosemide: may help to reduce
- Consider reducing Perindopril
- Review Amitriptyline - can contribute to falls

COPD

- Review COPD medications, consider a triple therapy inhaler (LABA/LAMA/ICS)
- Ensure rescue pack in place

Sleep

- Review Furosemide: check timings - ensure not being taken later in the day or evening
- Consider reducing Perindopril
- Review Amitriptyline - not seemingly helpful for sleep
- Review Atorvastatin - could try taking this in the morning as can cause sleep problems for some people
- Review COPD medications, consider a triple therapy inhaler

Diabetes

- Check he is taking his Metformin
- Consider DPP4i

The MDT review happens 'behind the scenes' but is informed by the information gathering appointment. This includes the care coordinator acting as an advocate for Eric highlighting the things that matter to him. This offers Eric access to a range of professional expertise without the need to see a vast array of professionals.

A fully functioning MDT is therefore crucial to the successful delivery of proactive care, however we wanted to design our approach to mitigate against some of the issues patients identify when faced with the proposition of an MDT[10].

Potential patient concern	**What we designed into our PCSP process**
Rationing of healthcare (not being able to see GP)	• Information to patients from GP practice explaining service and delivered in conjunction with/as part of local GP teams. • Services integrated into primary care MDT working, access to general practice for expert advice and support
Continuity, knowing who to contact and what to expect	• Key point of contact is the care coordinator • Explanation of the service and how it works (and helps) • Coordinating the care process to reduce the number of professionals involved and using the team as an expert resource
Multiple assessments - *"death by assessment"* and having to tell different members of the MDT the same things	• Single assessment process combining LTC and functional status, delivered by a trained individual using clinical systems to identify gaps in care • Developing an IT template to combine all these elements so they are only asked once
MDT team meetings used to make decisions about people and don't consider the needs of diverse groups	• Training in person centred care • Discovering what matters to people as part of the process and ensuring this is recorded and drives decisions • MDT review the information gathered from the holistic assessment ahead of PCSP – advice, ideas and options discussed; decisions not made ahead of PCSP conversation
An even greater group of professionals to navigate and unclear about people's roles	• Care coordinator and care planner draw on expertise of the MDT and bring this to the patient (rather than making referrals to new professionals) • Focus of care on what will make a difference and avoidance of multiple referrals where they don't add value to the person's life

How MDT and clinical review works in the programme PCNs

In **Carlisle Healthcare**, there is an established MDT for housebound people which has further developed as part of the expansion from the additional roles reimbursement scheme. The MDT is viewed positively and during process mapping we identified robust safeguarding measures to address urgent red flags. There is a 'clinician of the day' to deal with urgent issues and the co-located frailty nurses and occupational therapists are easily accessed by the care coordinators for informal advice, support and discussion of patients.

For those receiving planned care there is a weekly MDT meeting and cases can be discussed as part of that forum, however the maturity of the team and their co-location ensures that there is much informal discussion and support out with the formal MDT meetings.

In **Keswick & Solway**, the 'Your Health Matters' team of care coordinators is based within the ICC and managed primarily through the occupational therapy service. They are co-located with a range of other professionals including physiotherapists, dietitians and district nurses and can access informal support as needed.

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[10] https://www.nationalvoices.org.uk/sites/default/files/public/publications/a_shift_to_multidisciplinary_teams_in_general_practice.pdf

Within the community hub there is a daily huddle where the team discuss individual patients, share information and have access to a range of expertise relevant to the needs and concerns of the person. There is no doctor or nurse involvement in the daily huddle however the ICC also holds a monthly MDT, chaired by the clinical lead GP and attended by a range of health and social care professionals for more specific clinical advice and guidance.

The care coordinators are closely linked to GP practices and utilise existing processes to address any red flags or urgent issues. The 'Your Health Matters' team also has access to a practice pharmacist for support around medication.

Personalised care and support planning conversation

Care and support planning conversation

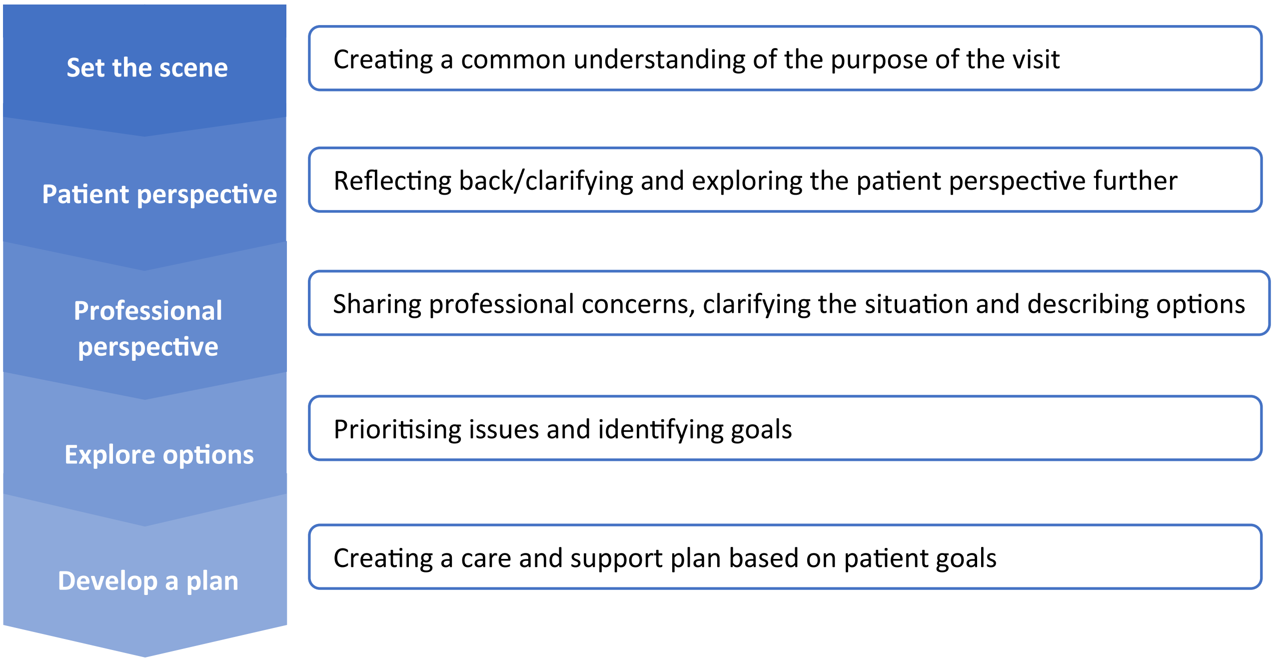
Contact with healthcare professionals usually happens because of illness or injury and forms a reactive acute episode of care. Proactive personalised care and support planning is different; it is based on relational rather than transactional, task focused, episodic care. It seeks to actively create opportunities for individuals to express preferences about their health and social care, and debate options around self-management, care and treatments and have this documented within the clinical record and patient held record.

This is about planning care with people and recognising their role in day-to-day self-care decisions, and supporting people to know what to do if their health deteriorates. As time goes on this includes people's preferences around end of life and place of care.

The personalised care and support planning conversation offers an opportunity for people and professionals to come together as equals and experts to consider ways people can manage their conditions and live well. An effective personalised conversation is based on developing trust and rapport and is enabled by preparation, giving people the opportunity to reflect on what is important to them (their own personal goals) and how they would like to live their life.

The Year of Care consultation framework was developed to create a structured approach to these conversations beginning with the patient's story and including professional concerns, building on the information gathering review. What matters to the person and their own goals are the focus of the conversation as outlined in Figure 7.

Figure 7 – *Structure of the personalised care and support planning conversation*



It became clear during the proactive care programme that the information gathering step was an opportunity to take a narrative based approach to assessment, and for the patient and care coordinator to work together to establish the key areas of concern for the person. This supports people to feel listened to, but also serves to determine the most appropriate professional to have the personalised care and support planning conversation. For example, if an individual has highlighted many concerns around management of their long-term conditions, a nurse may be best placed to have this conversation. If their concerns are mainly around function, then an occupational therapist may be more appropriate.

The professional can use the assessments and subsequent MDT discussion to help guide the professional aspects of the personalised care and support planning conversation however is very much a collaborative process, with involvement from families and carers if appropriate. The conversation should focus on health and care that is proactive and preventative and supports optimum outcomes for the person. This may include:

- What is important to the person in the context of their lives (highlighted through information gathering and preparation).
- The person's key concerns (highlighted through information gathering or preparation).
- Things they would like to be able to do or continue to do to live as well as possible. This may include functional tasks, accessing community activities (social prescribing), hobbies and interests.
- How the person is managing and living with their health conditions and what might be helpful in supporting them to manage these needs in the future. This may include managing falls risk, managing long-term conditions such as diabetes, having emergency health care plans in place and understanding what to do if a health issue arises.
- Introducing the topic of future health and care needs for example housing, lasting power of attorney, advanced decisions and resuscitation status.

The outcome of this conversation can be recorded on the patient held care plan which details goals and actions for both the person and the professional. Given the likely complexity experienced by this cohort of people and the holistic nature of the plan, it is recognised that involvement from one or more members of the MDT may be required to deliver or support the goals and actions. To reflect the principles of proactive care however some extension of roles may be helpful to minimise the number of professionals involved and reduce treatment burden for people.

What this means for Eric

Eric chooses to have his personalised care and support planning conversation with his daughter Fiona present, and the conversation is with an occupational therapist who has met Eric before.

At this review Eric hears about his test results and what they might mean for his medical conditions. He and Fiona can talk about their worries about his COPD, his falls and how hard he is finding getting a good night's sleep. They share that this is making him feel a bit down and he isn't confident to go out, because he has had some issues with continence. He also lets the professional know that he had a DNACPR form completed at the hospital, and he isn't sure what happens with the form and who needs to know about it.

He is supported to make decisions about the care and support he needs, including a referral to Age UK for advice about benefits and keeping warm in winter, getting some community transport to go out to the local leek club and his daughter offers a weekly shopping trip so he can choose his own groceries.

From a medical point of view, he isn't sure how to use his rescue medicines and the health care professional asks the community nurse to give him a written plan for this and talks though the medication with Fiona. His GP has also suggested another inhaler, and this is organised for him. The GP has looked though his medication and had suggested a reduction in some of his drugs to reduce his risk of falls and help him sleep better. Eric lets the professional know that he hasn't been good at remembering his medicines, so they discuss ways of handling this that suit Eric and Fiona.

To help him stay steady on his feet and to sleep better they discuss some practical ideas, including a handrail and some exercises he can do to improve his strength and balance.

The professional also adds details of his DNACPR form into the clinical record and asks him to keep this with his personalised care plan in case of an emergency.

Personalised care and support planning conversations in the programme PCNs

In **Carlisle Healthcare**, proactive care and support planning conversations are well established and undertaken by a nurse with a specialism in frailty. The conversation takes place after the information gathering appointment and following discussion with the care coordinator. The nurses have access to other members of the MDT and can review frailty, function and long-term conditions. There are currently no systems in place to consider the personalised care and support planning conversation to be undertaken by a different professional within the team.

The Your Health Matters team in **Keswick & Solway** is composed of care coordinators reporting to occupational therapists who work into the practices across the PCN. The personalised care and support planning conversation will therefore be undertaken by occupational therapists, in collaboration with the care coordinators who will focus on the information gathering part of the process. Since proactive care is wider than the traditional occupational therapy role it is hoped that the team will consider role extension, particularly around clinical issues and advanced care planning.

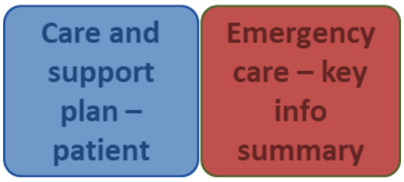
It was recognised in Keswick & Solway that practice nurses who usually focus on LTC reviews in practice may be asked to undertake the PCSP conversations with some patients and that it might be useful to consider:

- Introducing a Year of Care approach for people with long-term conditions who can access the practice (potentially introducing a single review approach for people with multiple LTCs)
- Consider adding aspects of anticipatory/proactive care planning not included in the current LTC/QOF style review into PCSP conversations. This involves verification of frailty and issues related to frailty such as falls and advanced care planning.

As part of implementation of the proactive care approach Year of Care provided training on personalised care and support planning conversations to both PCNs.

Care and support plans

Developing a patient held care plan



There was much discussion within the programme team and across the PCNs about the purpose of care plans. These are often written from a professional perspective, for the use of other professionals, and include jargon and information that is meaningless for people and their families or carers.

There was broad agreement that to be more personalised, the care plan should be held by the person and have a dual purpose; being relevant and clear for both the person whom the care plan is written about, as well as for professionals, particularly those visiting in emergency situations.

To design the care plan information was obtained from a variety of sources, including:

- Year of Care expertise and knowledge in developing resources for patients in a way that is personalised and useful in supporting them to manage their conditions and live as well as possible.
- Analysis of national examples, including the Scottish 'Key information Summary'.
- Analysis of regional tools and templates, including the 'Deciding Right' documentation and guidance.
- Discussion and updates from the team leading on the delivery of the Great North Care Record including content, spread, interoperability and access.
- Discussion and feedback from the Carlisle Healthcare team on their existing documentation, considering its usefulness in practice.
- Discussion with Keswick & Solway PCN about proposed content, including service user feedback.
- Patient feedback from a focus group attended by the Year of Care team.

An initial draft of a patient held care plan was created by Year of Care (Appendix 10). This included a 'key information summary' for ***professionals*** that featured 'what you would like people to know about you', 'what's important to you in an emergency situation' and 'what normal looks like'.

The care plan also contained key sections for the ***person***, including 'what you can do if your health suddenly gets worse' and a 'plan for living well' (patient goals). These sections are designed to reflect the outcomes of a personalised care and support planning conversation and act as an aide memoir. To ensure all future preferences about care and dying were included it was proposed that the Deciding Right documentation[11] would sit alongside the care plan.

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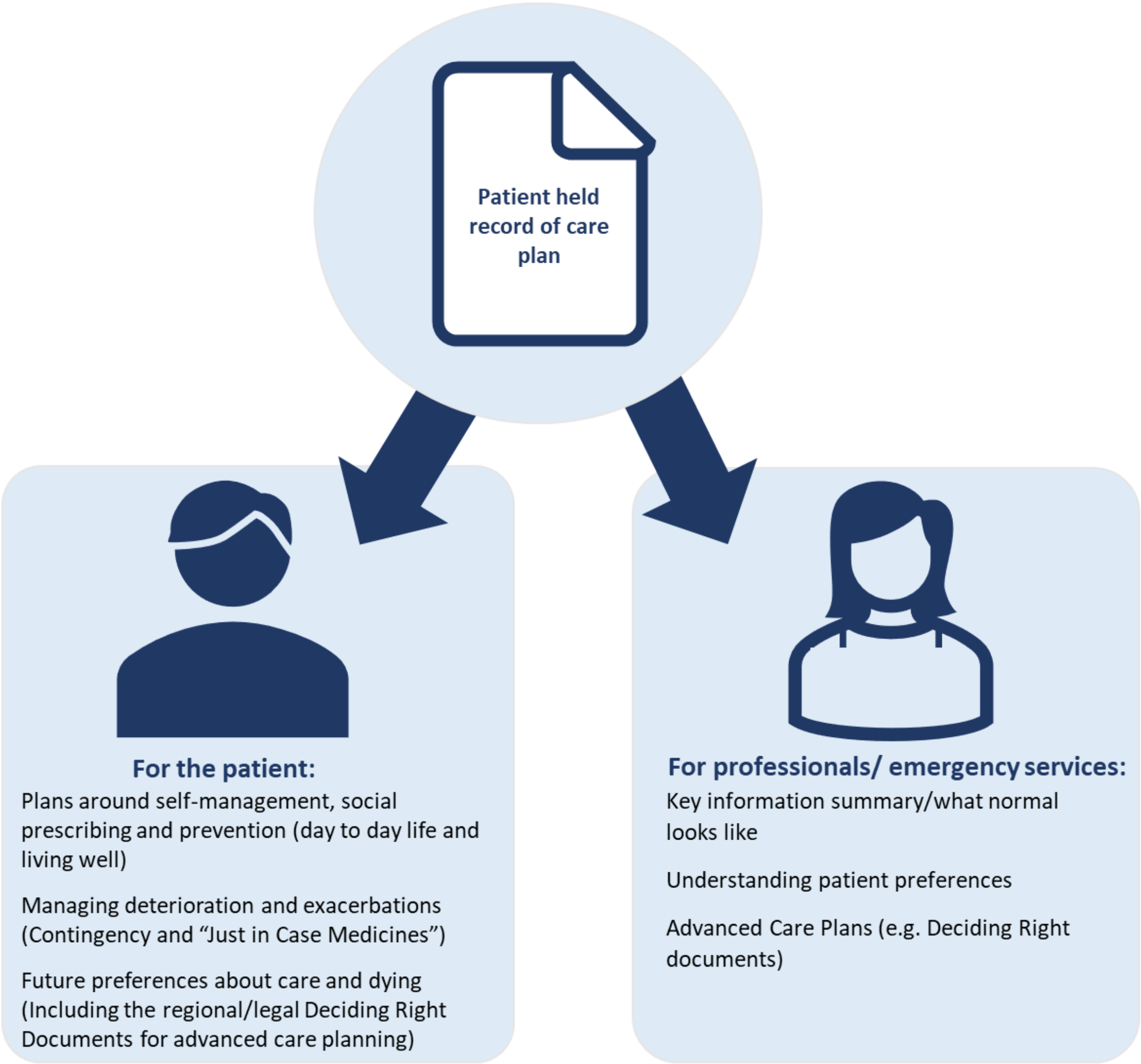
[11] https://northerncanceralliance.nhs.uk/deciding-right/deciding-right-regional-forms/

Figure 8 – *Patient held record of the care plan – sections for the patient and the professional*



For the patient:

Plans around self-management, social prescribing and prevention (day to day life and living well)

Managing deterioration and exacerbations (Contingency and "Just in Case Medicines")

Future preferences about care and dying (Including the regional/legal Deciding Right Documents for advanced care planning)

For professionals/ emergency services:

Key information summary/what normal looks like

Understanding patient preferences

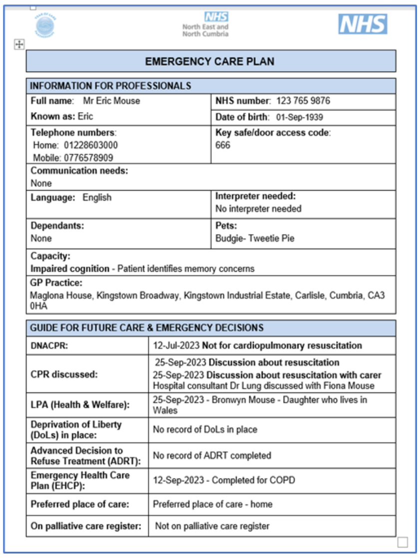
Advanced Care Plans (e.g. Deciding Right documents)

The care plan is used to document the decisions and actions which result from the proactive care and support planning conversation. Some parts of the care plan document are automatically populated from the IT data entry template and others are manually updated. The care plan can be printed and shared with the patient once complete.

We linked with the Great North Care Record team to ensure the advanced care planning document is available across services in an electronic form. This has not yet come to fruition and so it has been agreed that the documents would be shared to the out of hours services and a hard copy left in a prominent place in the patient's home, until the issue of electronic sharing of summary information can be resolved, specifically around advanced plans and wishes around end of life decisions and resuscitation.

Eric’s care and support plan

Eric keeps a copy of his plan and his DNACPR in a file in the house and is aware that this will be reviewed annually or sooner if necessary. The clinical record is updated to reflect the content of Eric’s plan.

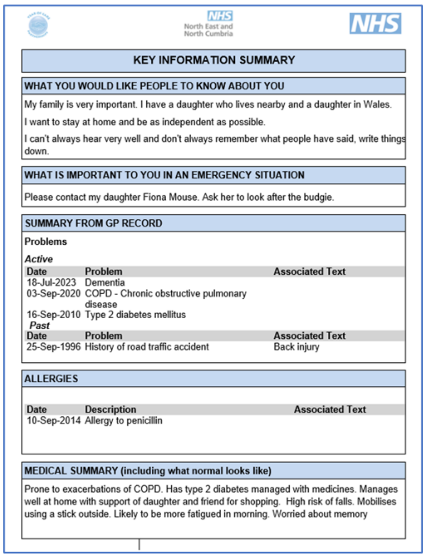


NHS North East and North Cumbria

EMERGENCY CARE PLAN

INFORMATION FOR PROFESSIONALS	
Full name: Mr Eric Mouse **Known as:** Eric	**NHS number:** 123 765 9876 **Date of birth:** 01-Sep-1939
Telephone numbers: Home: 01228603000 Mobile: 0776578909	**Key safe/door access code:** 666
Communication needs: None	
Language: English	**Interpreter needed:** No interpreter needed
Dependants: None	**Pets:** Budgie- Tweetie Pie
Capacity: **Impaired cognition** - Patient identifies memory concerns	
GP Practice: Maglona House, Kingstown Broadway, Kingstown Industrial Estate, Carlisle, Cumbria, CA3 0HA	

GUIDE FOR FUTURE CARE & EMERGENCY DECISIONS	
DNACPR:	12-Jul-2023 **Not for cardiopulmonary resuscitation**
CPR discussed:	25-Sep-2023 **Discussion about resuscitation** 25-Sep-2023 **Discussion about resuscitation with carer** Hospital consultant Dr Lung discussed with Fiona Mouse
LPA (Health & Welfare):	25-Sep-2023 - Bronwyn Mouse - Daughter who lives in Wales
Deprivation of Liberty (DoLs) in place:	No record of DoLs in place
Advanced Decision to Refuse Treatment (ADRT):	No record of ADRT completed
Emergency Health Care Plan (EHCP):	12-Sep-2023 - Completed for COPD
Preferred place of care:	Preferred place of care - home
On palliative care register:	Not on palliative care register



NHS North East and North Cumbria

KEY INFORMATION SUMMARY

WHAT YOU WOULD LIKE PEOPLE TO KNOW ABOUT YOU

My family is very important. I have a daughter who lives nearby and a daughter in Wales.

I want to stay at home and be as independent as possible.

I can't always hear very well and don't always remember what people have said, write things down.

WHAT IS IMPORTANT TO YOU IN AN EMERGENCY SITUATION

Please contact my daughter Fiona Mouse. Ask her to look after the budgie.

SUMMARY FROM GP RECORD

Problems

Active

Date	Problem	Associated Text
18-Jul-2023	Dementia	
03-Sep-2020	COPD - Chronic obstructive pulmonary disease	
16-Sep-2010	Type 2 diabetes mellitus	

Past

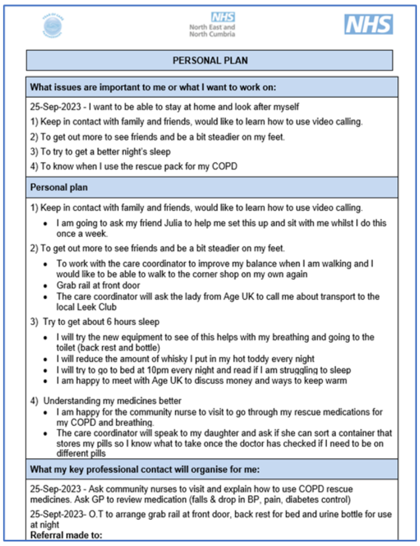
Date	Problem	Associated Text
25-Sep-1996	History of road traffic accident	Back injury

ALLERGIES

Date	Description	Associated Text
10-Sep-2014	Allergy to penicillin	

MEDICAL SUMMARY (including what normal looks like)

Prone to exacerbations of COPD. Has type 2 diabetes managed with medicines. Manages well at home with support of daughter and friend for shopping. High risk of falls. Mobilises using a stick outside. Likely to be more fatigued in morning. Worried about memory



NHS North East and North Cumbria

PERSONAL PLAN

What issues are important to me or what I want to work on:

25-Sep-2023 - I want to be able to stay at home and look after myself

1) Keep in contact with family and friends, would like to learn how to use video calling.

2) To get out more to see friends and be a bit steadier on my feet.

3) To try to get a better night's sleep

4) To know when I use the rescue pack for my COPD

Personal plan

1) Keep in contact with family and friends, would like to learn how to use video calling.
  - I am going to ask my friend Julia to help me set this up and sit with me whilst I do this once a week.

2) To get out more to see friends and be a bit steadier on my feet.
  - To work with the care coordinator to improve my balance when I am walking and I would like to be able to walk to the corner shop on my own again
  - Grab rail at front door
  - The care coordinator will ask the lady from Age UK to call me about transport to the local Leek Club

3) Try to get about 6 hours sleep
  - I will try the new equipment to see of this helps with my breathing and going to the toilet (back rest and bottle)
  - I will reduce the amount of whisky I put in my hot toddy every night
  - I will try to go to bed at 10pm every night and read if I am struggling to sleep
  - I am happy to meet with Age UK to discuss money and ways to keep warm

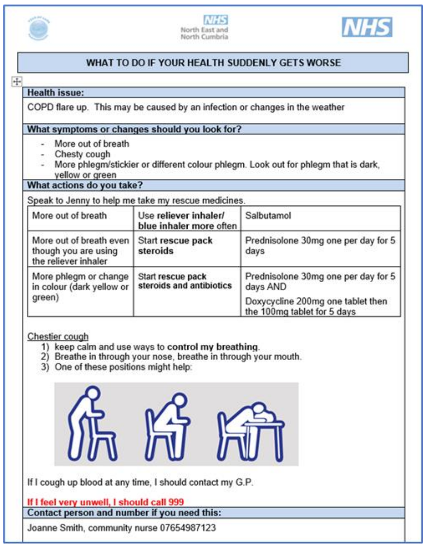
4) Understanding my medicines better
  - I am happy for the community nurse to visit to go through my rescue medications for my COPD and breathing.
  - The care coordinator will speak to my daughter and ask if she can sort a container that stores my pills so I know what to take once the doctor has checked if I need to be on different pills

What my key professional contact will organise for me:

25-Sep-2023 - Ask community nurses to visit and explain how to use COPD rescue medicines. Ask GP to review medication (falls & drop in BP, pain, diabetes control)

25-Sept-2023- O.T to arrange grab rail at front door, back rest for bed and urine bottle for use at night

Referral made to:



NHS North East and North Cumbria

WHAT TO DO IF YOUR HEALTH SUDDENLY GETS WORSE

Health issue:

COPD flare up. This may be caused by an infection or changes in the weather

What symptoms or changes should you look for?

- More out of breath
- Chesty cough
- More phlegm/stickier or different colour phlegm. Look out for phlegm that is dark, yellow or green

What actions do you take?

Speak to Jenny to help me take my rescue medicines.

More out of breath	Use **reliever inhaler/ blue inhaler more** often	Salbutamol
More out of breath even though you are using the reliever inhaler	Start **rescue pack steroids**	Prednisolone 30mg one per day for 5 days
More phlegm or change in colour (dark yellow or green)	Start **rescue pack steroids and antibiotics**	Prednisolone 30mg one per day for 5 days AND Doxycycline 200mg one tablet then the 100mg tablet for 5 days

Chestier cough

1) keep calm and use ways to **control my breathing**.
2) Breathe in through your nose, breathe in through your mouth.
3) One of these positions might help:

If I cough up blood at any time, I should contact my G.P.

If I feel very unwell, I should call 999

Contact person and number if you need this:

Joanne Smith, community nurse 07654987123

Ongoing review and care coordination

The proactive care approach targets individuals living with more complex needs. These people are likely to have many teams and services involved in their care and this may be fragmented and feel overwhelming for the person. Effective care coordination is therefore an integral part of proactive care to ensure people receive care that is more joined up, consistent and relevant to need.

This involves coordinating care in line with the patient’s views and wishes and may include:

Ongoing review, care coordination and support dependent on needs and patient preferences

- Utilising the MDT and expertise of others to minimise the number of people and interventions involved. The patient should have choice and control and only have things ‘done to them’ that are in line with clinical need and their wishes.
- Having an advocate for the person within the system, ensuring they have a voice, and their views are heard.
- Helping people to work towards their goals and objectives. This may involve creating connections with the right people at the right time and can include support for traditional services such as dentistry, dietetics and physiotherapy, alongside social prescribing and community activities accessed via the voluntary sector.

Dedicated care coordinators have the time, capacity, and expertise to support people to navigate the complex health and social care system. They are also able to develop strong links with the local community providers/voluntary sector to enhance the options for community support for this cohort of people. This will ensure a range of activities are available dependent on interests, hobbies and abilities and may include options such as walking, singing groups or activities such as ‘knit and natter’ and ‘men in sheds’.

Most people identified for proactive care will be living with progressive long-term conditions and some degree of complexity. As such, it was agreed by all that these individuals would not receive an episode of care but instead they would remain on the caseload indefinitely. This offered the opportunity for regular review and ongoing care coordination.

Ongoing review and care coordination for Eric

PCSP is not a one-off review, people like Eric remain on the anticipatory/proactive care register and will be reviewed at least annually or at intervals agreed in the plan. Eric will be seen by the community nurse based on his concerns about his COPD and will have some support from Age UK about heating his home and accessing community transport. At any time he needs to he can contact his care coordinator or access usual NHS services.

Through this process he has a few visits from a small team who know him well, and if his health or function deteriorates, he has some contingency plans in place to manage these. He also has his advanced wishes noted should his health deteriorate significantly.

How ongoing review and care coordination works in the programme PCNs

There is a dedicated care coordinator in **Carlisle Healthcare** and the wider team work together to achieve care coordination through MDTs, daily huddles and co-location. The care coordinator knows individuals on the caseload well and are often the first point of contact. Patients are offered annual reviews as part of proactive care with the care coordinator completing the information gathering visit. However, since the Carlisle Healthcare team focus on those who are housebound, they are often required to support other preventative services such as vaccinations. This can take priority and impact upon the ability of the team to undertake routine personalised care and support planning.

Keswick & Solway will have a team of five care coordinators in total, and four of these will support clinical practice, with one person focusing on systems and administration.

Care coordinators will work closely with occupational therapists and the GP practices to share information and represent the views of the person to inform the personalised care and support planning conversation.

Once a care plan has been written, it is envisaged the care coordinator will work closely with the person to help them to achieve their goals; this may be through practical support in terms of functional practice (rehab or reablement) or setting up links to the voluntary sector and other organisations.

Since the service is new, it is planned that reviews will happen annually or bi-annually, dependent on need. The breadth and scope of the role will be evaluated and adapted as the service develops.

Chapter 6: Key findings and lessons from development, training and implementation

Year of Care worked closely with the PCN teams to facilitate, mentor and train as they worked through the process of implementation. Meetings, training sessions and ongoing communication presented valuable information and important lessons that can inform future roll out. These are summarised in the table below with more detailed learning provided later in this chapter.

Coherence and purpose

- It is important for organisations to understand and agree the purpose of proactive care and the expected benefits for the patient group, including a clear understanding about what is meant by personalised care and how that will be applied to each individual patient.
- It is important for recruitment, induction of new team members, teamworking, processes, patient resources and training to be underpinned by this understanding.
- Organisations and team members need to see the value of proactive planned care set against acute access pressures.
- Having an established method of offering people with multiple long-term conditions a single personalised care and support planning process within a PCN proved to be a good foundation to build the delivery of proactive care, in terms of coordination, process, and ethos.
- Identifying the proactive care population, including the numbers and levels of complexity, should inform the planning of the service, including the roles and skill mix of the team.

IT and digital

- The RAIDR case finding tool can be useful in identifying the proactive care population, however issues with frailty coding and how health inequalities are identified may impact on the validity of the search results.
- The proactive care cohort identified in the RAIDR dashboard is likely to be large in number; it may be necessary to agree local criteria to prioritise those with greatest need. Local intelligence is also useful in identifying those who may benefit from proactive care e.g. those using high levels of unplanned care or where proactive care could be integrated into existing reviews.
- It is important for the team delivering proactive care to have access to the GP clinical system.
- It is also important that a single data entry template is used to record assessments and care plans to avoid duplication - a data entry template has been developed for EMIS Web to support the delivery of proactive care.
- Careful thought needs to be given to how templates are used to complete holistic assessments so that they remain ‘conversational’ and that this doesn’t become a professionally driven task.
- Work needs to be done to enhance digital sharing of care plans across the system including the ambulance service, out of hours services and secondary care, to prevent duplication and ensure the patient voice is heard.

Delivering the process of proactive care

- People are identified for proactive care based on searches therefore careful thought should be given to how we introduce and describe the offer to support engagement.
- Having a process that separates out assessments from care and support planning conversations is important to avoid assessments dominating planning appointments.
- Preparation materials that describe ‘what to expect’ and offer people the opportunity to prepare for their conversations with health care professionals are important, supporting patient involvement and prioritisation of the patient agenda within personalised care and support planning.
- Information gathering and MDT review support the identification of both patient and clinical priorities and inform which team member is best placed to do the personalised care and support planning review.

- It is essential for teams to have an established process for responding to urgent issues or red flags with appropriate medical support to handle risk and uncertainty.
- The care and support planning conversation should focus on supporting the person to live well and manage exacerbations, alongside thinking about future care decisions. This should be recorded on the personalised care and support plan and shared with relevant organisations in the health care system.
- The care and support plan has two core functions; to help the patient navigate healthcare and manage their own health, *and* to provide information including advanced preferences in an emergency to acute care services. However, care plans are often written about the patient rather than for/with the patient. Both functions are important and gaining clarity about this is vital for those supporting patients to develop their own care plans.
- People in this cohort should not receive 'episodes of care' but rather tailored reviews and support to coordinate their care and meet their changing needs until the end of their life.

Role and remit of the multidisciplinary team (MDT)

- This work is new and so new roles/posts, administration and associated costs need to be funded.
- Urgent care often takes priority over planned proactive care; if possible, services delivering proactive care should be distinct from those delivering urgent response to ensure this important work isn't devalued or demoted.
- The proactive care cohort is complex and requires a core multidisciplinary team of professionals who have expertise in frailty and long-term conditions. Support from a wider multidisciplinary team, including senior medical and prescribing support, is also essential.
- Effective proactive care requires good care coordination which can be achieved as a function of the MDT or through having dedicated care coordinators. Both approaches require close MDT working and the opportunity to draw on expertise from other professionals.
- Where possible the team delivering proactive care should be integrated into the primary care team and ideally co-located to support learning, development and easy access to support.
- Having close links to, and support from, voluntary third sector organisations can enhance the delivery of personalised proactive care.

Workforce training and extension of roles

- Training around the delivery of personalised proactive care can support successful implementation of the programme and ensure coherence and fidelity about how it is delivered.
- The MDT needs a range of roles and functions which are routed in expert generalists with knowledge around frailty, long-term conditions and advanced care planning.
- Support to extend roles and develop an appreciation of new roles can be enabled through both training and close working with other MDT members.
- The care coordinator is a novel role and includes a range of complex activities. A comprehensive training and development programme is required to support competency development.

The key learning and themes around implementation are explored further on the following pages.

Coherence and purpose – implications for team working

The programme launch events and staff evaluation indicated that there was a strong level of coherence amongst teams about why they wanted to do things differently, the importance of personalised care and the benefits that it could bring to patients. However, as the programme developed it was clear that there was less coherence about the detail of how this could be delivered and what it entails, and it was necessary to revisit the principles and purpose of the programme frequently throughout implementation.

Understanding the complexity of the group of patients and their varied needs is required at an early stage to influence team recruitment and composition, as well as skill mix, governance, and supporting infrastructure to truly reflect the principles of proactive care, without which there is a real risk that the skills of the professionals rather than the needs of the patient will dictate the care provided. Limitations in the roles that can be recruited via the ARRS scheme also restricted some of the recruitment options particularly around advanced nursing roles including frailty.

In the new Keswick & Solway proactive care service the team did not have allocated support for long-term condition management and within the individual practices long-term condition care was often delivered by different nurses who focused on specific long-term conditions, which has potential to increase the number of health care encounters each individual patient has. This may have been due to limited recognition of the role of proactive care in reducing treatment burden and the number of professionals involved in a person’s care. This also made it was more challenging to integrate medicines management and advanced care planning into the proactive care process.

In Carlisle Healthcare, they were well established in delivering the Year of Care approach to personalised care and support planning for people with single and multiple long-term conditions. This was an enabler in terms of developing and extending the programme to the proactive care population and long-term condition management was integrated into their existing approach, however adapting this to include all the people identified by initial searches was challenging.

There had been a loss of focus on planned care during the pandemic aggravated by retirement of a key staff member and therefore fewer team members actively focusing on proactive care with no capacity to increase the caseload. The team has benefited from new team members recruited through the ARRS scheme, however maintaining focus on the purpose of this work has been challenging as new members have joined the team. Some of the primary care team members did not value the planned nature of the work, despite support from senior leadership, which alongside pressures from acute work meant at times the team are pulled in to support other functions, such as vaccinations.

This is exacerbated by the national DES which focuses on primary care access rather than planned and proactive care. This indicates a strong need to separate out and prioritise planned services to ensure that proactive care can be delivered to those who will benefit.

IT and digital

The digital support and IT systems were a significant enabler for this programme. Not having these in place at the outset delayed the initial implementation of the programme. There were some successes and some areas for learning.

Population health data: The RAIDR dashboard provides population health data to give PCNs an indication of patient numbers and potential case load, but it was only when this data was used to identify individuals in practice registers that it ‘came to life’. Having access to this data earlier in the programme would have helped understand the people within the recommended proactive care cohort, and ensure teams recruited the appropriate skill mix of staff to handle the complexity and issues that people lived with. For Keswick & Solway, who were recruiting a new team, this may have helped in planning the scope of the service and influenced recruitment of the MDT to ensure the right combination of skills and roles. For Carlisle Healthcare this would have allowed the team to understand the relationship between their current cohort of patients and those identified using the tool, including those not identified by the usual practice processes and those who would additionally benefit from the service.

Coding: It is acknowledged that across the region there are variations in the accuracy of coding and verification of frailty. The RAIDR tool uses coded frailty data to identify individuals who might benefit from proactive care. Carlisle Healthcare were already utilising the Clinical Frailty Scale (Rockwood) routinely in practice to verify frailty, however this was less well established in Keswick & Solway. This meant that data on frailty was unreliable for Keswick & Solway, creating an issue with accuracy within the RAIDR dashboard. The Year of Care team delivered training to staff on the verification of frailty and further work is needed to embed this in practice. The introduction of the local frailty identification method made available towards the end of the programme within EMIS Web may help to address this issue.

In addition to frailty, there were issues around identification of people living with health inequalities since this was based on postcode captured in clinical systems alone.

Proactive care cohort: The RAIDR dashboard initially identified a large group of people across the inclusion criteria and so to manage the caseload each PCN focused on specific groups and used local criteria to augment the process. In Carlisle Healthcare, there was limited resource and so the focus remained on the housebound group. Keswick & Solway tried different approaches and with experience of seeing patients in their own homes have identified that people in moderate and severe frailty groups may benefit most from the approach.

Both teams developed a local method alongside the search tool to identify individuals who might benefit from proactive care, with local intelligence as outlined in Chapter 3. There is a risk that using local criteria to refine the group and make numbers manageable may exclude some individuals who could benefit from the service and/or limit the proactive care ambition to reduce use of unplanned care.

It is important to note that some of those identified by the RAIDR dashboard may already have regular care as part of routine LTC reviews or are seen within other services such as specialist care, and so the PCNs reviewed the lists and removed those people. For people with long-term conditions who are already well known to the GP practice there is an opportunity to include the additional elements of proactive care within their routine annual personalised care and support planning reviews. Practice staff may need training or support around some elements such as frailty, multiple long-term conditions and advanced care planning however this would reduce duplication and improve equity for patients.

The PCN teams raised concerns about the accuracy of the identification of people living with health inequalities by postcode alone. Excluding health inequalities risks missing a cohort of people who may benefit from this approach however, and who may present with frailty and multiple long-term conditions at an earlier age.

The national criteria for proactive care at the time of this programme excluded some groups, e.g. people living in care homes and those identified as living with mental health conditions and no other LTCs. The assumption being that these groups were in receipt of proactive care from other teams or national schemes in a way that considered both their physical and mental health together. Both teams felt that this programme should overlap with the care home work and that this group should not have been excluded from the searches. This was because the proactive care work was often being delivered by the same teams with similar needs in terms of frailty and proactive care planning.

Functions of the RAIDR dashboard: The RAIDR dashboard has been found to be useful in general and critical to the delivery of this programme. Keswick & Solway have been accessing it regularly and use it to identify their potential cohort. However, the feedback from Carlisle Healthcare was that it was time consuming to run the searches and to then generate patient level data. They opted to run their own local searches and continue to use local intelligence and clinical judgement to identify those for the service. In the future offering PCNs options around how they identify patients for this programme may be useful.

Developing the IT template: This was developed in EMIS Web with input from many partners and has two core functions around information gathering (assessments) and documenting care and support plans. Access to a team who can develop, and update templates was critical to the delivery of the programme since existing templates didn't enable or support the process of proactive care.

The information gathering template is reflective of all the components of the comprehensive geriatric assessment (CGA) and includes tests for long-term condition monitoring. The template is smart and will only display the information required for the conditions people live with, but despite this there are several pages to complete. This template is separated out from the personalised care and support planning template to reflect the overall process.

During the programme it became evident that clinical staff don't always understand the functionality and limitations of the IT system (e.g. the recording of problems using codes) versus the need to record detailed assessment information. Developing the template with new staff helped reinforce the purpose of the programme and revisit these principles again. Ongoing review is recommended to adapt the template accordingly, but in the context of its purpose and function. Once the template has been refined a SystmOne version would be helpful so that all practices can access this in the future.

Using the IT template: Both teams have begun to use the new template and the feedback has been largely positive however the template is lengthy and there is a lot to complete. Through training, staff have been encouraged to see assessment as an ongoing process where all elements don't need to be completed at the first or second visit. CGA is designed to be multidisciplinary and ongoing, with information recorded at an appropriate time. The teams have been supported to collect information in a conversational way, led by the patient to support a sense of control and balance of power. This will not be possible if the template is used as a checklist to guide the assessment and it is imperative that this is covered in training for any future implementation.

There were challenges faced by teams in terms of interoperability of different systems across different organisations and clinical governance. These were overcome by having the teams access and record information within the primary healthcare record in general practice.

Delivering the process of proactive care

It is important to have a process that is understood by the proactive care team, the GP practice and the patient. This programme identified some key elements that are important for effective delivery:

Invitation and explanation of the programme: The patient cohort are identified by professionals and systems rather than by patients asking for a service, support or advice. The teams had to carefully consider how patients were approached and what was said about the service. In general people responded better to conversations (on the phone) than to leaflets or texts. It was also important that the team delivering proactive care was seen as aligned to the GP practice and that the benefit of this way of working could be articulated to the patient by all members of the team. Patients were uncertain about the benefits of non-traditional roles (social prescribers and care coordinators) and unfamiliar roles (occupational therapists).

Clinical review of case notes (access to clinical record): Ideally the proactive care process should include clinical review of case notes, using a checklist or with medical input. In Carlise Healthcare the care coordinator worked closely with a senior medic and frailty nurses and had developed an understanding of what to look out for. Newer teams who were not co-located found this more difficult and relied on 'tasks' in clinical systems to raise questions and used the red flag system within the GP record to note outstanding tests and tasks. To ensure the inclusion of LTC management as part of proactive care, the teams felt that access to the GP clinical system was essential to ensure sufficient information is shared and effective processes are in place for easy identification of tasks and tests which are required for good clinical care.

Patient preparation: As this is a new way of working, patients needed to be supported and encouraged to use preparation materials as part of the process. Both teams found this was helpful in giving patients time to think about what is important to them, with this being used to frame conversations and reduce the burden of assessment during their visits. There was some useful feedback on the preparation materials; the front sheet (Appendix 7) was widely used, however few patients completed the 'Things that are bothering me' section. Indeed, some of the staff had noted that patients cancelled visits after receiving the more detailed documentation.

Information gathering, including knowledge and awareness of 'red flags': As many of the patients on the proactive care caseload are living with complex needs, it is important for those completing information gathering appointments to have some knowledge and awareness of clinical 'red flags' and what to do if they present; this may include acute illness or safeguarding issues. It is also important that staff can access medical advice and support in a timely way. In Carlisle Healthcare, there are clear lines of medical accountability and access to GP advice through the hub doctor. In Keswick & Solway this was less well established and so more difficult to navigate across the PCN.

The personalised care and support planning conversation: Learning from the programme clearly indicated that the PCSP conversation should focus on three elements: living with and self-managing conditions, managing exacerbations and decisions about future care. Feedback from the teams indicated that these three elements were rarely completed within one conversation, mainly due to time and skills of the health care professional. In Keswick & Solway the conversations were with an occupational therapist who did not feel they had the knowledge or skills to support the development of a plan to manage exacerbations and sought advice from nurses within the GP practice. This was considered an effective and proactive way to work and reduced duplication through information sharing, however. Both teams began to introduce decisions about future care within the conversation, however it was clear that further training and support would be beneficial to implement this fully into practice. Consideration and access to professionals who can complete Emergency Health Care Plans (EHCP) and DNACPRs is important to embed proactive care in practice.

The care and support plan: When developing the patient held plan, it was agreed that this should reflect the discussion within the personalised care and support planning conversation and act as an aide memoir for the patient. It should also act a guide for professionals in an acute or emergency situation. The aim for the care plan was that it would be linked to the proactive care template so that some sections could be populated via the EMIS Web system. This was largely successful, however there were some issues in relation to system limitations, such as restrictions on the number of characters which could be used in a single domain. This meant that for sections which required more detail free text had to be used to create clarity for the patient. The PRIMIS team created a 'how to' guide to help the teams to navigate this more easily.

In terms of the content of the care plan, teams initially started adding large amounts of information, however during training exemplar care plans were shared to help staff create more concise and focused care plans. This helped staff see the types of information it was useful to include and the benefits of keeping it concise for both patients and professionals. Patient evaluation of the care plan has not been completed and this would be beneficial in the future.

The care plan is important for the patient, but it is also important for professionals in emergency situations. The teams expressed concerns that out of hours services such as NWAS and CHOC were not able to access this plan electronically and may not be aware of its existence. This was addressed by creating 'alerts' on the GP system for the out of hours services and ensuring advanced care plans were coded as 'problems' within the IT data entry template, however no evaluation or feedback has been sought in relation to this. In future the aim is to make the care plan available via the Great North Care Record to reduce duplication and improve flow of information between services.

Ongoing review and care coordination: Both teams recognised that individuals are not 'discharged' from a caseload; they receive ongoing care coordination and review. Reviews could be completed annually or sooner - this would be dependent on need. Care coordination is key in supporting people to navigate the system, to reduce duplication and access care that is appropriate and required by the person. This can be achieved as a function of the team or through having dedicated care coordinators in post. Having a named contact for non-urgent queries was seen as beneficial.

Interventions and support: One of the important aspects of personalised care and support planning is to work with people to find out what their goals are and then identify appropriate support or interventions. Options discussed should be varied and wide ranging to reflect the broad needs of the population and include traditional and non-traditional options. Both teams had close access to social prescribers and local voluntary organisations which were considered crucial in supporting self-management. Having a social prescriber as a core part of the integrated neighbourhood team is considered essential for this group of patients.

Role and remit of the multidisciplinary team (MDT)

The PCNs recognised that those who may benefit from proactive care are likely to have complex needs and current receive uncoordinated care from a range of professionals and providers. The proactive care framework highlights the importance of MDT working as this complexity means that care cannot be provided by a single professional. Whilst many patients are already known to the practice and it is acknowledged that proactive care has the potential to save money and reframe existing work, it does also constitute 'new work' which requires investment and bespoke/distinct MDT teams. Both PCNs have accessed funding to develop new teams and employ new staff, and delays in recruitment, including developing new job roles and job descriptions delayed the start of the programme in one PCN.

Members of the core team: In Keswick & Solway the team was developed from ARRS funding and so although they recruited skilled practitioners, this limited the roles that could be recruited. This meant that there was a lack of medical, nursing and long-term condition knowledge and expertise within the core team. It was acknowledged by the PCN early in the programme that a frailty nurse (or equivalent) would be useful to support the team, however there was no resource to provide this, and it created several challenges during implementation. The core team acknowledged the need for direct senior medical support in terms of handling risk, understanding prognosis and medical priorities, as well as offering an oversight of care. In Carlisle Healthcare, the team has a dedicated frailty nurse and access to GP support which has been beneficial for the delivery of proactive care.

Both teams have dedicated care coordinators who are responsible for undertaking the ‘information gathering’ step of the proactive care process. In Carlisle Healthcare, this is established and works very well as the care coordinator has a vast amount of experience in delivering this approach and has excellent knowledge around long-term conditions and functional issues. There was recognition from both teams that the role of the care coordinator needs careful thought so that it contributes to care coordination by bringing together a range of tasks usually completed separately or as part of other care pathways.

Both teams have reported that there is a large amount of administration associated with the delivery of the service which takes time away from clinical care. The Keswick & Solway team are in the process of recruiting a care coordinator to manage these demands, including RAIDR searches. It would be useful to evaluate this role in the future.

MDT support: In Carlisle Healthcare there was an established functioning MDT that was largely co-located with access to advice from other team members. A weekly MDT meeting provided the opportunity for supervision and support and there was access to emergency advice and support via the Hub doctor. We found this offered the Carlisle Healthcare team access to safety netting, advice and support, with clear lines of accountability. In Keswick & Solway, these functions were not yet established. The occupational therapists were aware of how to refer patients for an urgent review and initially started to request support for non-urgent issues via tasks in EMIS Web. The team felt this was not beneficial in terms of developing relationships or conferring the complexity of the issues and have subsequently begun to visit practices for face-to-face conversations with both GPs and practice nurses. They are working hard to develop awareness of the service and overall this has had benefits in terms of joined up working and improving knowledge around medical aspects of care however this is still done on an ad hoc basis. Without the prospect of a formal MDT meeting in the future this may impact care and so should be a consideration for any future roll out.

Medicines management and optimisation: Many of the patients involved in the programme have complex medication regimes which could ideally be reviewed as part of this process, including understanding all the issues the patient is living with. Both teams have had access to pharmacy support, but the ease of access and level of integration into the process has led to varying success in including medicines management. In Carlisle Healthcare this works well through the established MDT model, although it is an area they wanted to formally improve through participation in the programme. In Keswick & Solway there have been some early challenges due to access and service limitations. The team raise concerns around medication with the PCN pharmacist via tasks on clinical systems which has sometimes led to poor communication of the issues and understanding of the purpose of the service, which has in turn impacted on working relationships. It is therefore essential that when proactive care services are being developed the issue of meaningful medicines expertise and management is considered at the outset as polypharmacy will be a common issue for many patients.

Composition and development of the MDT: Generally, it was agreed that contracts between organisations and arrangements within PCNs need to be flexible to allow role development which focus on reducing the burden of care for the patient rather than being rigid about what different organisations/professionals will or will not do. These are now being referred to nationally as ‘integrated neighbourhood teams’, and ideally these need to be part of the wider primary healthcare team.

Our learning has identified that the team should always include administration, care coordinators, nursing roles and AHPs with access to meaningful support and supervision from GPs and prescribing support. Given the complexity of the caseload the MDT team need to include a range of roles/functions and be rooted in expert generalists:

- Care coordination and administration
- Long-term conditions expertise, including the ability to complete physical tasks and tests such as foot checks, phlebotomy, BP measurements, vaccinations etc. as part of the process
- Medicines management and support with issues arising from polypharmacy
- Frailty and support around function and activities of daily living
- Social prescribing and linking with the voluntary sector
- Advanced care planning including professionals who can legally complete DNACPR and other aspects of advanced care planning

MDTs need to share their expertise, learn from each other and offer ideas but not to make decisions without or on behalf of the patient. It was important that the different team members developed an appreciation of the skills of others and understood where to access information, advice and support.

In particular, the role of care coordinator needs to be supported and nurtured. Individuals in these roles are often new to practice, have novel roles and are asked to take on complex activity which includes being able to communicate effectively with both professionals and patients, perform physical tests and assessments, support the patient to navigate healthcare and some routine social prescribing activities. This is best achieved when individuals are supported though formal training and are part of a supportive MDT who offer supervision and mentorship.

Advanced Care Planning: At the outset of the programme, it became clear that there was a lack of awareness in some of the wider PCN groups about the distinction and overlap between proactive care (wide range of planning activities) and advanced care planning (specifically around end of life). As the programme progressed, the teams in Keswick & Solway and Carlisle Healthcare were encouraged to think about how advanced care planning could be included in the process as an essential part of proactive care. This required careful thought in terms of understanding Deciding Right, and the roles/training required to embed it in practice.

Workforce training and extension of roles

Having a coherent view of the purpose of proactive care and the skills and knowledge in the workforce to deliver it is a key to successful delivery. Given the complexity of the cohort, staff need to have knowledge around many aspects of care and have access to appropriate advice and expertise to support learning in practice.

Workforce: It was evident during the programme that a role in proactive care was seen as attractive, with many of the staff joining the proactive care teams from other local frontline roles. This however created recruitment issues in other areas that may impact on delivery of other services.

Personalised care and support planning training for staff: the tailored training delivered by the Year of Care team was well evaluated with staff reporting a positive learning experience. Such training would be beneficial for any team looking to roll this out in the future in terms of helping them understand the national frameworks, underpinning philosophy, process, and skills required to deliver personalised proactive care. Case studies proved useful in highlighting how the process worked, the responsibilities of different team members at different stages of the process and developing an awareness of the need for clinical training. Alongside the formal training sessions, the teams also greatly benefited from access to facilitation support and relevant expertise.

Clinical training: to successfully deliver a proactive care service staff need to be trained in several clinical areas, including frailty, long-term conditions, medicines management and polypharmacy, advanced care planning and personalised care approaches such as social prescribing. As different professionals complete tasks and functions, this training needs to be tailored to their role. For example, care coordinators may need to be taught phlebotomy and care and support planners need to be able to interpret the results of a core range of blood tests.

Care coordinator role: Carlisle Healthcare have an established care coordinator in the team who had a high level of knowledge around all aspects of proactive care including long-term conditions and frailty. They have meaningful conversations with patients, identify red flags, and undertake tests and assessments. This person was deemed crucial in the delivery of the service. In Keswick & Solway, the care coordinators were new in post and are developing their competencies in this area. Early indications suggest it takes time and a great deal of support for care coordinators to develop the knowledge and skills required for the role. They also need to be clear about their role and be supported by a wider team. This requires some consideration in terms of future roll out.

Role extension: The proactive care process is unique as it combines many elements of a person's care to reduce duplication, treatment burden and to improve outcomes for patients. This includes completing a holistic assessment to inform the personalised care and support planning process. Within the programme there were a lack of options in terms of which professional could take the lead in the care and support planning process; in Carlisle Healthcare the only option was the nurse, in Keswick & Solway it was the occupational therapists. Given that many people will have complex needs, this may demand some extension of roles within the teams to support delivery. For example, in Carlisle Healthcare the new frailty nurse may benefit from training in advanced care planning in practice and in Keswick & Solway the occupational therapists may benefit from developing their knowledge and expertise around polypharmacy and long-term condition management. The EnCOP framework combined with more detailed long-term condition guidance may support this.

Wider team: Throughout the pilot programme we often discussed those who were already attending practice for their routine LTC reviews. This offers an opportunity for the practices to build on this approach and include some of the proactive care elements however may require some additional training and support for staff. In Keswick & Solway, the PCN are still largely offering disease specific reviews and so training and facilitation support for a multimorbidity approach may be helpful in the future.

Other

An initial draft framework for anticipatory care was released in August 2022 supported by a community of practice by NHS England. The final proactive care guidance was released in December 2023 when there were significant changes in the cohort and core components. This created uncertainty during the programme term and will require review and consideration for sites looking to implement this in the future.

It is important to acknowledge that although we have gained a vast amount of learning about how to deliver proactive care during this programme, formal evaluation of impact has not been undertaken. The PCNs are hoping to capture patient feedback and to monitor quantitative outcomes such as hospital admissions, emergency call out, use of unplanned care etc. for further evaluation.

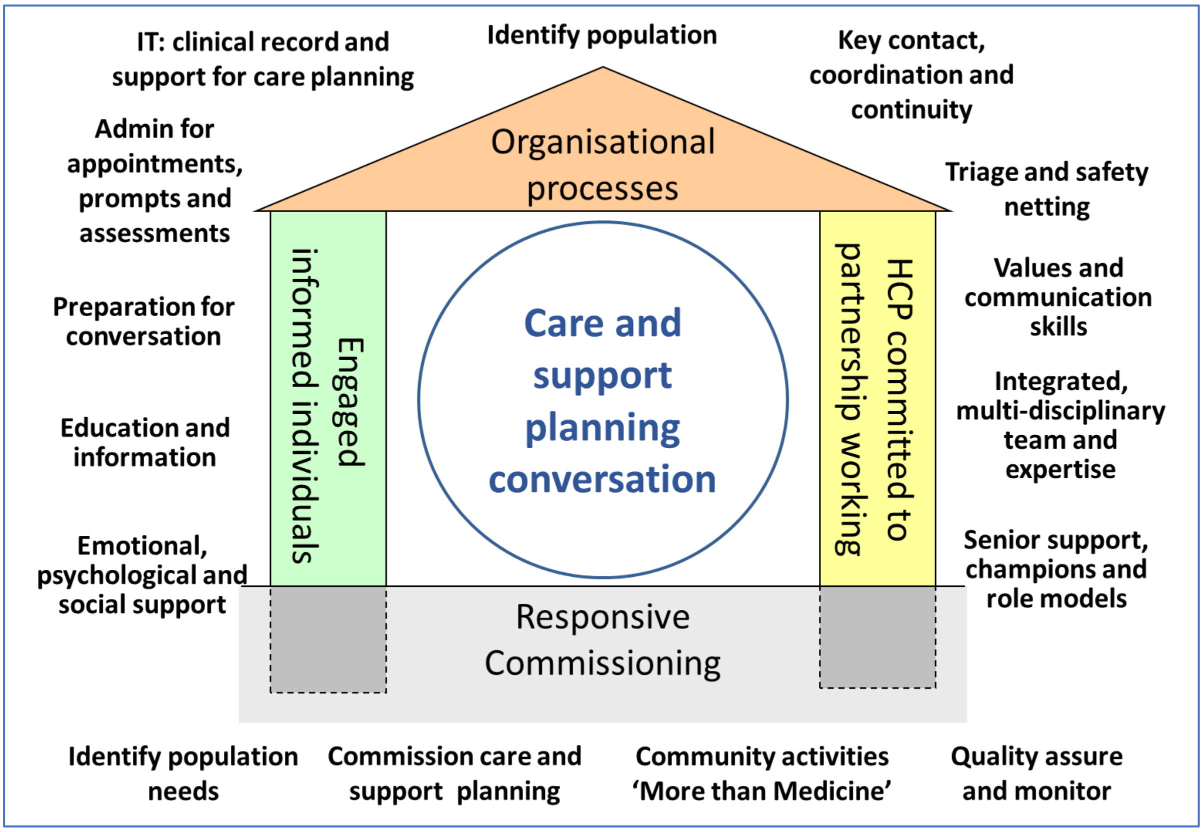
Chapter 7: Recommendations and considerations for implementation of proactive care

As we have developed this programme of work, we have been able to identify enablers and recommendations for implementation of proactive care approaches across a healthcare system. Some of the specific tools developed are summarised and made available in the Proactive Care Toolkit[12].

This learning forms the basis of our recommendations about what is needed to implement high quality proactive care across a neighbourhood or health system. This chapter summarises the key considerations to take account of when setting up and establishing a proactive care team and process and should be considered with the lessons for implementation in Chapter 6.

The Year of Care House in Figure 9 has been used as a summary of these activities and resources.

Figure 9 *– The Year of Care House*



To ensure that individuals who are likely to benefit from proactive care receive this in a structured and organised way, there needs to be a method of identifying and inviting people, clear care processes which describe the roles and responsibilities of individual team members and digital support and training to enable this to happen.

This can be described across four domains represented in the Year of Care House but needs to be delivered by teams who are signed up to the value of proactive working, the philosophy of personalised care and who see the importance of this way of working set against other more acute pressures in the healthcare system.

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[12] Please contact enquiries@yearofcare.co.uk for access to the Proactive Care Toolkit

In other words, the bricks of the house are cemented together by an underlying philosophical approach to people that is fundamentally person centred and with a strong clarity of purpose around the role of the work and the benefits it brings to people and the health care system.

What needs to be in place

Items identified with an asterisk* are available in the proactive care toolkit.

Organisational processes

The key organisational elements required to deliver proactive care include:

Teams and space

- An identified multidisciplinary team that meets regularly, are supported by senior clinicians and work in an integrated way across the health care system.
- The separation of proactive planned care from unplanned urgent care, to ensure proactive care remains a priority in a pressurised healthcare system.
- Space and a working environment for teams to work alongside each other so that they can have formal and informal opportunities to learn and share their individual expertise and knowledge of the patient group they serve. Ideally teams should be co-located and have direct access to support from other team members with communication in person rather than via tasks or electronic communication.
- Administration function to support the team around meetings, access to clinical information and general administration of the programme including inviting people, being a single point of contact and sending information about appointments and preparation materials. In some teams this forms part of the role of the care coordinator.

IT tools and systems

- Tools to support the accurate coding of frailty and its clinical validation to ensure accurate identification of individuals for the programme*.
- Electronic searches* which support the identification of people who might benefit from being invited to join the programme including searches augmented by local methods which identify individuals using local clinical intelligence.
- Appropriate codes* embedded into templates which identify who has been invited to take part in proactive care, who declines and codes to acknowledge when care plans have been developed including methods to identify specific advanced care plans (see Appendix 5).
- A data entry template* which integrates into the general practice clinical systems and includes all the assessments and tests which need to be completed as well as the documentation of the agreed shared care plan (December 2023 for EMIS Web).
- A patient facing personalised care and support plan, including information for use in an emergency which can be populated from the clinical record*.
- A method of sharing holistic assessments and all types of personalised care plans, including advanced care plans, with emergency services, out of hours services etc.

Workforce and integrated team working

The development of new teams, including new members of staff in novel roles requires senior leadership, oversight and structured training and support. The new members of staff need to be clear about the purpose of the work they are asked to do and be prepared to learn, develop and extend their role with support from a fully functioning MDT, including medical oversight to maintain overall accountability for the work of the team and to handle risk and uncertainty.

This seems to work best where teams are co-located and have regular meetings, with supervision and informal support as and when questions or issues arise. This won't happen by chance and so this work needs to be carefully managed and planned.

The multidisciplinary team (MDT/integrated neighbourhood team)

- Search tools are used to assess the needs of the population and the mix of staff that might best support the anticipatory/proactive care approach.
- There is a senior doctor who supports the team and offers high level support on complex clinical issues.
- With a focus on frailty the core team consists as a minimum of administration, care coordinators, social prescribers, frailty nurse with expertise in long-term condition care and occupational therapists.
- Structured support needs to be offered to care coordinators who are often new to practice, have novel roles and are required to take on a range of complex activities (Appendix 9). This may be best managed via the development of a regional training programme.
- The team is routinely supported by an experience prescriber who has expertise in issues around frailty and polypharmacy (potentially a GP, pharmacist, or advanced nurse practitioner).
- The core team acts as a hub to coordinate care and they access other professionals and the third sector according to need, often asking for advice and guidance and only arranging further face to face reviews where there is a need for practical support and advice e.g., Age UK, Specialist Nurses, Dietitian, Physiotherapist, Speech and Language Therapist, Palliative Care.
- New teams would benefit from service development sessions to look at how the process would be applied in their care setting and to develop local implementation plans including how the service will be evaluated.

Training, mentorship and induction of new team members

- Overall understanding of the role of the proactive care approach and how it benefits individual patients and the healthcare system (the micro and macro picture).
- The proactive care and support planning process, and associated tools and IT systems*.
- The philosophy, style, skills and structure of a personalised care and support planning approach/conversation and how to document the personalised care and support plan*.
- Long-term conditions (knowledge and skills of the core long-term conditions, their routine monitoring and management, including self-management and medication).
- Identification, assessment and management of frailty, including the Rockwood Frailty Scale and the CGA.
- Advanced care planning and using the local Deciding Right tools (note these can only be used by trained and approved professionals).

The EnCOP framework[13] will include many of the competencies related to frailty and would need to be commissioned alongside other training which focuses on personalised care and support planning and long-term condition care.

Support for individual patients

People are identified for proactive care based on searches produced from clinical systems rather than on request which may be bewildering so careful thought needs to be given to:

- How the programme is introduced and described to people, balancing the offer of support and coordination with maintaining people's independence and supporting unmet need - careful thought should be put into the words used to describe the programme*.
- Preparation materials which describe 'what to expect' and offer people the opportunity to prepare for the personalised care and support planning conversation by identifying the topics or issues they wish to discuss*.
- Access to both statutory services and the voluntary and third sector, according to the needs and preferences of the individual.
- A personalised care and support plan* written so people understand their care better, know what to do if their health deteriorates, have their voice heard and have their preferences around end-of-life care documented and shared with relevant organisations in the health care system.

Infrastructure and support across organisations

Some elements of delivery of this programme would be best procured and organised at a regional level, to give consistency and to avoid duplication of work. These include elements such as IT, searches and regional templates but also training, monitoring and evaluation of the implementation of proactive care to assess the effectiveness of further implementation. What's needed:

- Incentive schemes to promote this way of working, which clarify how it is different from existing work and how it fits with national NHS objectives/regional drivers.
- Agreed SNOMED codes, searches and practical guidance on the identification of the proactive care cohort*.
- IT data entry templates with embedded coding that document the proactive care process and associated care plans, alongside methods to share care plans with key care providers linking into the Great North Care Record.
- Funding for new roles, including the ARRS roles, but with support for the development of community frailty nurses (not formally included within the ARRS role scheme).
- Job descriptions and role descriptions which can be shared to enable easier recruitment of individuals into roles.
- Facilitation and support to set up processes and develop coherence in teams*.
- Structured training (as above) made available regionally.
- Agreed metrics to monitor and assess the impact of the programme.
- Case studies, learning events and networks to share the work as it moves forward.

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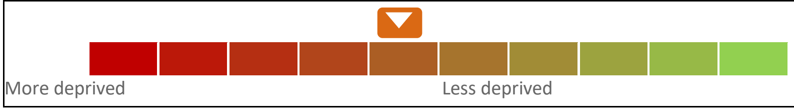
[13] https://frailtyicare.org.uk/making-it-happen/workforce/enhanced-care-of-older-people-with-complex-needs-encop-cpmpetency-framework/

Appendices

Appendix 1 – Practice profiles and search data

Carlisle Healthcare PCN practice profile

Carlisle Healthcare PCN	37,064
QOF achievement	599 (out of 635)
Life expectancy (Male)	77.5 years
Life expectancy (Female)	81.9 years
% having a positive experience of their practice	73.7%

Deprivation
Fifth more deprived decile


Ethnicity Estimate
1.2% Asian

Carlisle Healthcare PCN search data

	Experiencing Health Inequalities	**Frailty (Moderate or Severe)**	**Reliant on unplanned care**
Aged over 18 with 2 or more LTCs	1787	1317	209
2 or more non-elective emergency admissions	32	36	25
Admission risk (High/Very High)	352	378	45

Keswick & Solway PCN practice profiles

Keswick & Solway PCN	42,319
QOF achievement	612.1 (out of 635)
Life expectancy (Male)	81.1 years
Life expectancy (Female)	83.3 years
% having a positive experience of their practice	89.2%

Deprivation
Fifth more deprived decile

Ethnicity Estimate
0.7% non-white ethnic groups

Keswick & Solway PCN search data

	Experiencing Health Inequalities	Frailty (Moderate or Severe)	Reliant on unplanned care
Aged over 18 with 2 or more LTCs	467	672	192
2 or more non-elective emergency admissions	10	25	36
Admission risk (High/Very High)	168	222	47

Appendix 2 - Evaluation report

Formal evaluation of the programme was carried out by Northumbria University who appointed Prof Darren Flynn and Dr Debra Morgan to conduct a service evaluation.

The aim was to explore the views and experiences of staff from the PCNs involved in the organisation and delivery of the Personalised Anticipatory/Proactive Care Programme (using the Year of Care approach to PCSP) to capture learning around implementation issues and processes using Normalisation Process Theory (NPT).

Project Report_PAC
evaluation_v9 04.10.2

Appendix 3 – Programme launch events

Carlisle Healthcare PCN

The Carlisle Healthcare session was attended by 21 staff from a range of backgrounds working within 3 teams across the PCN network. This included the specialist frailty service (Carlisle Network), the care home visiting team and the frailty team (Carlisle Healthcare PCN). The session was successful in building enthusiasm and there was recognition that some elements of proactive care and support planning were still in place. However, it was clear that there had been some loss of momentum owing to the pandemic and recent expansion of the team, associated with the creation of new ARRS roles. Whilst these roles offered the opportunity to expand the expertise within the team, and improve the reach of the programme, there was recognition that work needed to be done to ensure clarity around purpose of the work and the roles of different members of the MDT. Some key actions that were identified were:

- Understanding the cohort: The teams are already doing proactive care planning work; however, the scope of the work did not align with the nationally agreed anticipatory care group. Early baseline assessments were recommended to give teams a feel of the workload and requirements. It was recognised that this could be supported through the regional case finding tool.
- Reviewing the processes and documentation; including considering how new MDT roles can support delivery. There was also a desire to reduce the overall burden of assessment and ensure these were separate to the conversation.
- Training: there was recognition that there was a need to train the relevant professionals in personalised care and support planning skills relevant to the national frameworks

Keswick & Solway PCN

There was a good level of representation at the Keswick & Solway event, with 27 staff attending from a range of professional backgrounds, including GPs, practice nurses, pharmacists, and community staff.

There were however some evident inconsistencies relating to the reach and scope of the programme including confusion over anticipatory or proactive care and advanced care planning, and differing ideas about purpose, and who to include. There was an acknowledgement that further work was required to develop the programme. This included:

- Refining the cohort- There was blue sky thinking that “everyone” would benefit from some form of proactive care and support to live well; however, it was acknowledged that limited resource may define to cohort moving forwards. EMIS Web searches and the regional tool would help to give an idea of numbers and the potential target groups (i.e., the proactive care group) with an aspiration to roll the approach out to other groups of patients in the future (i.e., Year of Care approach to routine LTC care in practice)
- Developing the process in detail including supporting resources. This would include thinking through how people are identified and invited to the programme, how the MDT works including new roles and the patient materials in terms of preparation and documentation of the care plan.
- Clarity around anticipatory or proactive care versus advanced care planning was also required, owing to confusion in the literature
- Integrating the roles of existing members of the team with new staff (care coordinators and occupational therapists) and the wider MDT. Many roles in the ‘Your Health Matters’ team were still at recruitment stage and there was a lack of clarity at this point as to what their roles would entail within the new service and how the MDT would function around them.

- Accountability: managerial structures had been clearly established however there were no clear decisions relating to clinical accountability for this population. At this point, the team were considering long-term condition management as sitting outside of the care coordinator role, which may not be reflective of a personalised, holistic approach to care.
- Training. There was an acknowledgement that tailored training would be required for the staff around the delivery of personalised care and support planning and national frameworks around this group of patients.

Appendix 4 - Training Evaluation Summary

Number of evaluation forms completed - 10

On a scale of 1-10 (with 1 being ‘did not help at all’ and 10 being ‘very helpful’)

1. How much did training help you to understand the Year of Care approach to personalised care and support planning?

Poor	1	2	3	4	5	6	7	8	9	10	Very good
							1	2	3	4	

2. How much did training help you to reflect on your own approach/philosophy of care and how it fits in with personalised care and support planning?

Poor	1	2	3	4	5	6	7	8	9	10	Very good
						1		1	4	4	

3. How much did training help you understand the benefits of preparation for personalised care and support planning?

Poor	1	2	3	4	5	6	7	8	9	10	Very good
						1	1	1	2	5	

4. How much did training help you to understand the structure and skills of the personalised care and support planning conversation?

Poor	1	2	3	4	5	6	7	8	9	10	Very good
								3	2	5	

5. How much did training help you understand personalised goal setting and action?

Poor	1	2	3	4	5	6	7	8	9	10	Very good
							1	1	5	3	

6. How much has training helped you to reflect upon and develop your personalised care and support planning conversation skills?

Poor	1	2	3	4	5	6	7	8	9	10	Very good
						1		1	3	5	

What aspect of today’s session did you find particularly useful?

- Trainers very knowledgeable
- Breaking things down, not always looking at it all at once.
- Discussions around care planning, gaining support from other colleagues and bringing in input/advice/input without overloading the patient.
- Putting everything we do into a care plan and seeing the template completed knowing to keep it concise rather than trying to explain everything in depth.
- Collaborating with other teams/ professionals. Sharing ideas. Role play
- The reflection times and demonstrations
- Putting timeframe on visits. Supporting patient to identify own goals and problem solving.
- Role play. Putting into practice. Handout/copy of care plan
- Setting the scene, breaking erics problems down. Setting goals
- All of it, I have done it before but nice to refresh

What will you do differently following training?

- Ask more questions with patients and dig deeper into what is important to them.
- Setting the scene, time frame

- Support team to build better links with local services.
- Offer a time frame, give the patient the space to talk and make suggestions rather than offering suggestions straight away.
- Set more goals with patients. Allow patients to get more involved in their care. Get other professionals on board.
- Try things out in practice.
- Reduce amount written in care plan to ensure it is relevant for other professionals.
- Allowing more patient choice. Create links with other professionals to improve process.
- Timing, breaking the concerns down.
- Make sure patient is in control and make decisions.

What could have been improved?

- N/A
- I think there was a lot of information in a long session I struggled to take it all in so I'm looking forward to the slides being emailed over so I can refer back.
- More shorter sessions
- Listening more to individual feedback templates/ care plan structure – how meets individual service.
- Nothing, really enjoyed and learned a lot.
- N/A

On a scale of 1-10 (with 1 being 'poor' and 10 being 'very good')

How would you rate the session overall?											
Poor	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**Very good**
							2		2	6	

Would you recommend this training to a colleague embarking on personalised care and support planning? (✓)	**Yes**	**No**	**Not answered**
	10		

Appendix 5 – SNOMED codes for use in tracking anticipatory/proactive care and personalised care and support planning

Anticipatory/Proactive Care SNOMED codes:

- 1365271000000107 - Under care of anticipatory care service (finding)
- 1365301000000105 - Provision of anticipatory care service declined
- 1365281000000109 - Discharge from anticipatory care service
- 702779007 - The Emergency Health Care Plan (EHCP)
- 450476008 - Do not attempt Cardiopulmonary Resuscitation (DNACPR)
- 816301000000100 - Advance Decision to Refuse Treatment (ADRT)

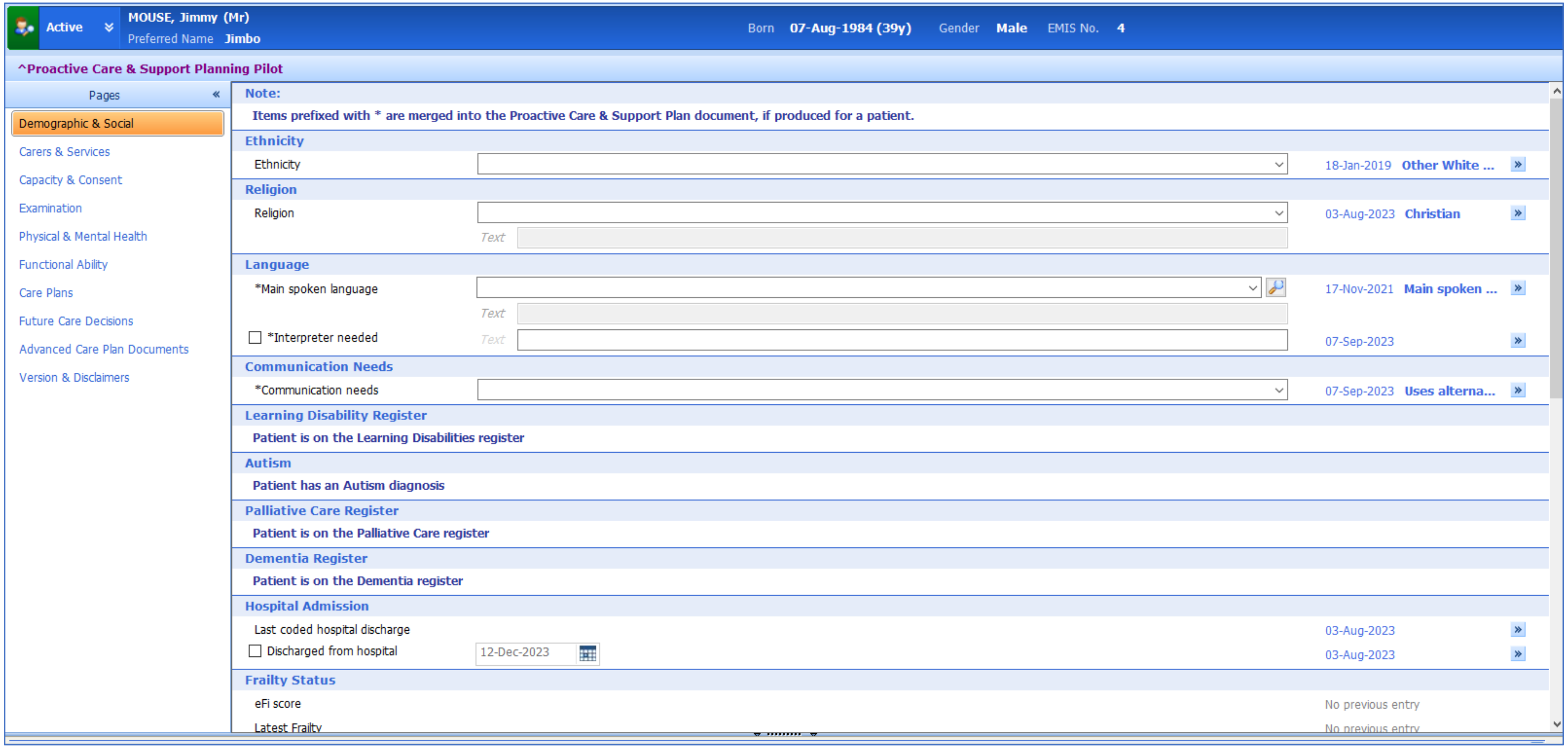
Personalised care and support planning SNOMED codes:

There are two new codes for personalised care and support planning (PCSP) that were introduced into the SNOMED-CT directory on 1 April 2020 however and so these should be used for tracking.

- 1187911000000105 - Personalised care and support plan agreed
- 1187921000000104 - Review of personalised care and support plan

Appendix 6 – Screenshots of the Proactive Care and Support Planning EMIS Web template

Demographics & Social



MOUSE, Jimmy (Mr)
Preferred Name **Jimbo**
Born **07-Aug-1984 (39y)** Gender **Male** EMIS No. **4**

^Proactive Care & Support Planning Pilot

Note:

Items prefixed with * are merged into the Proactive Care & Support Plan document, if produced for a patient.

Ethnicity

Ethnicity — 18-Jan-2019 **Other White ...**

Religion

Religion — 03-Aug-2023 **Christian**

Text

Language

*Main spoken language — 17-Nov-2021 **Main spoken ...**

Text

☐ *Interpreter needed — Text — 07-Sep-2023

Communication Needs

*Communication needs — 07-Sep-2023 **Uses alterna...**

Learning Disability Register

Patient is on the Learning Disabilities register

Autism

Patient has an Autism diagnosis

Palliative Care Register

Patient is on the Palliative Care register

Dementia Register

Patient is on the Dementia register

Hospital Admission

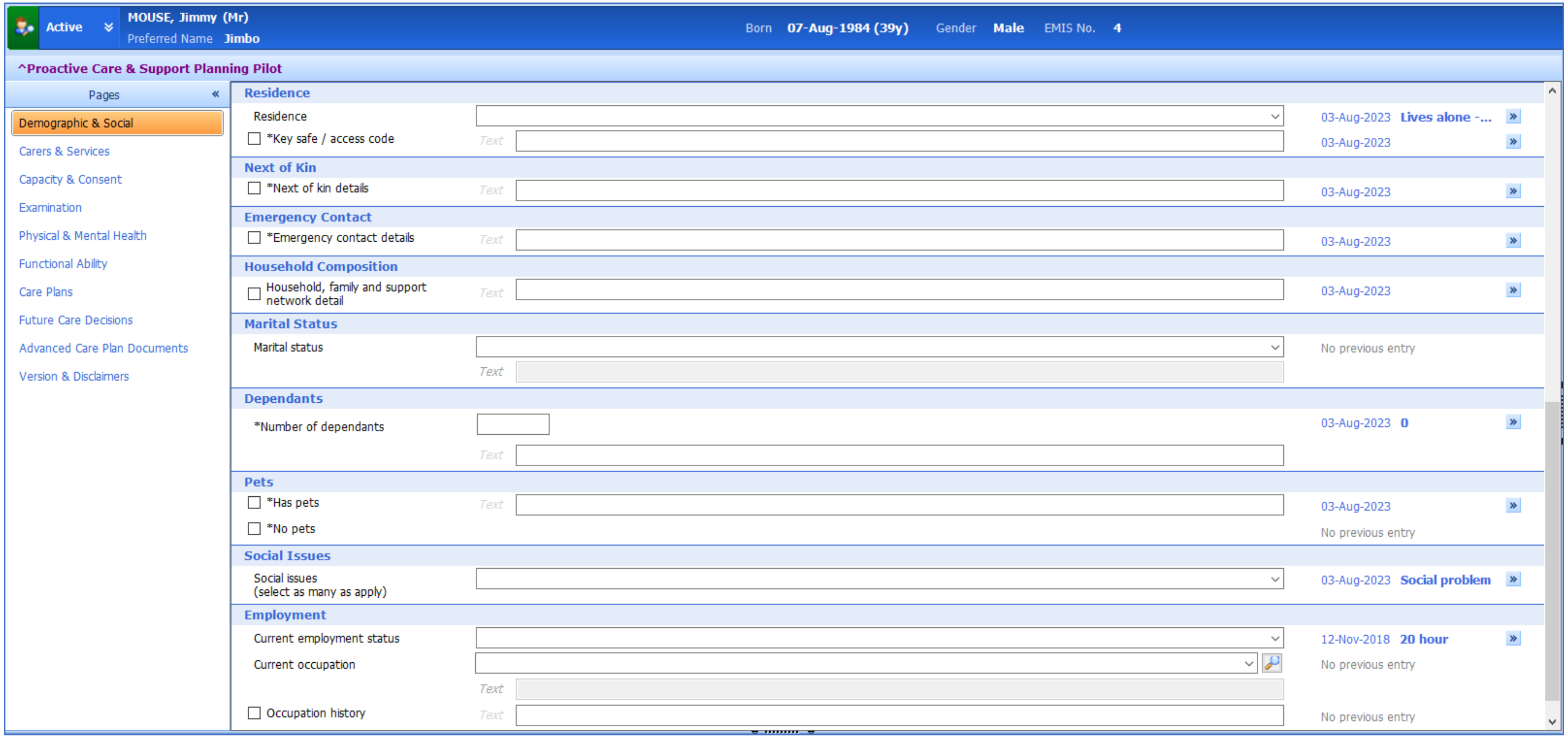
Last coded hospital discharge — 03-Aug-2023

☐ Discharged from hospital — 12-Dec-2023 — 03-Aug-2023

Frailty Status

eFi score — No previous entry

Latest Frailty — No previous entry



Active

MOUSE, Jimmy (Mr)

Preferred Name **Jimbo**

Born **07-Aug-1984 (39y)** Gender **Male** EMIS No. **4**

^Proactive Care & Support Planning Pilot

Pages

- Demographic & Social
- Carers & Services
- Capacity & Consent
- Examination
- Physical & Mental Health
- Functional Ability
- Care Plans
- Future Care Decisions
- Advanced Care Plan Documents
- Version & Disclaimers

Residence

Residence — 03-Aug-2023 **Lives alone -...**

☐ *Key safe / access code — Text — 03-Aug-2023

Next of Kin

☐ *Next of kin details — Text — 03-Aug-2023

Emergency Contact

☐ *Emergency contact details — Text — 03-Aug-2023

Household Composition

☐ Household, family and support network detail — Text — 03-Aug-2023

Marital Status

Marital status — No previous entry

Text

Dependants

*Number of dependants — 03-Aug-2023 **0**

Text

Pets

☐ *Has pets — Text — 03-Aug-2023

☐ *No pets — No previous entry

Social Issues

Social issues (select as many as apply) — 03-Aug-2023 **Social problem**

Employment

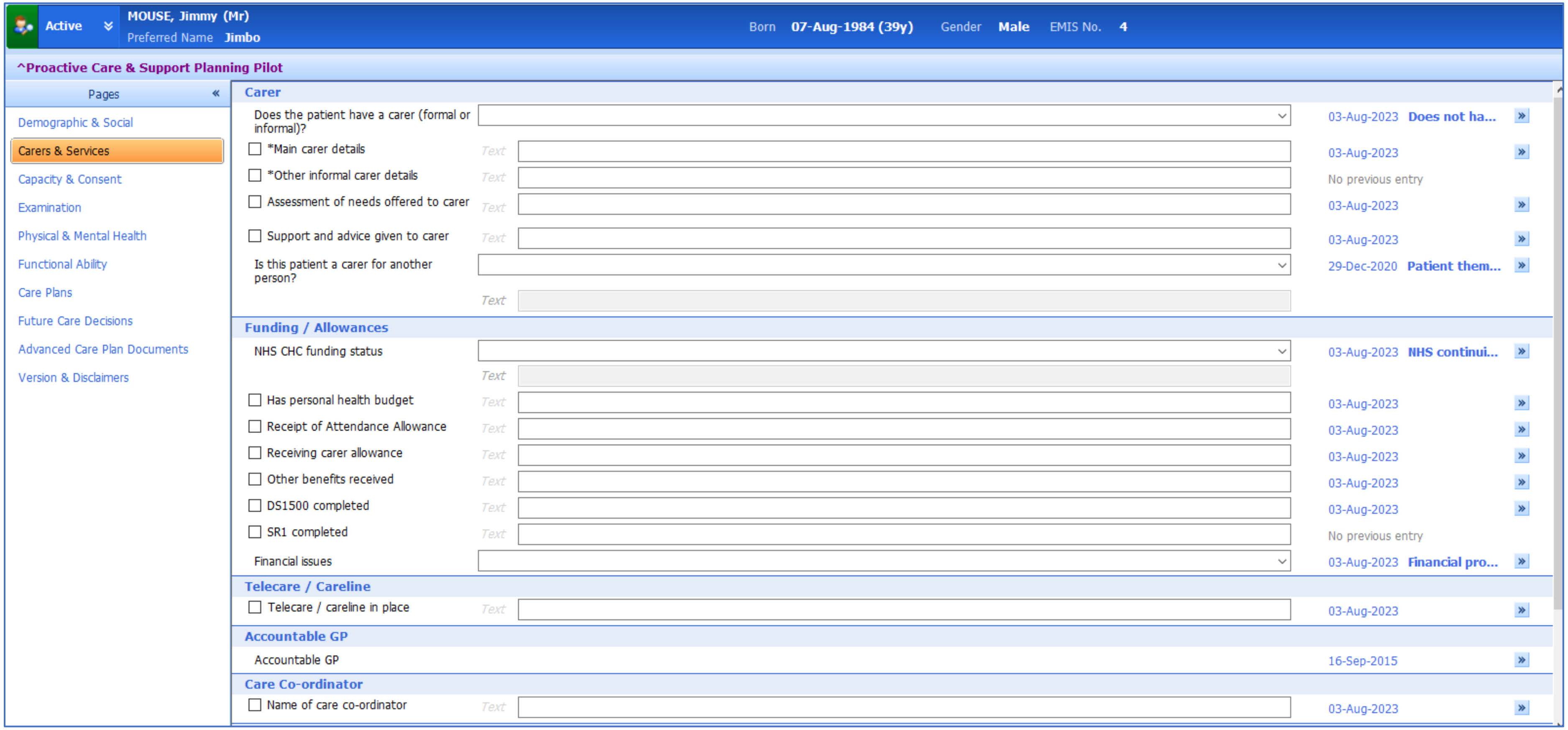
Current employment status — 12-Nov-2018 **20 hour**

Current occupation — No previous entry

Text

☐ Occupation history — Text — No previous entry

Carers & Services



MOUSE, Jimmy (Mr) Preferred Name **Jimbo** Born **07-Aug-1984 (39y)** Gender **Male** EMIS No. **4**

Carer

Does the patient have a carer (formal or informal)?		03-Aug-2023	**Does not ha...**
☐ *Main carer details	Text	03-Aug-2023	
☐ *Other informal carer details	Text	No previous entry	
☐ Assessment of needs offered to carer	Text	03-Aug-2023	
☐ Support and advice given to carer	Text	03-Aug-2023	
Is this patient a carer for another person?		29-Dec-2020	**Patient them...**
	Text		

Funding / Allowances

NHS CHC funding status		03-Aug-2023	**NHS continui...**
	Text		
☐ Has personal health budget	Text	03-Aug-2023	
☐ Receipt of Attendance Allowance	Text	03-Aug-2023	
☐ Receiving carer allowance	Text	03-Aug-2023	
☐ Other benefits received	Text	03-Aug-2023	
☐ DS1500 completed	Text	03-Aug-2023	
☐ SR1 completed	Text	No previous entry	
Financial issues		03-Aug-2023	**Financial pro...**

Telecare / Careline

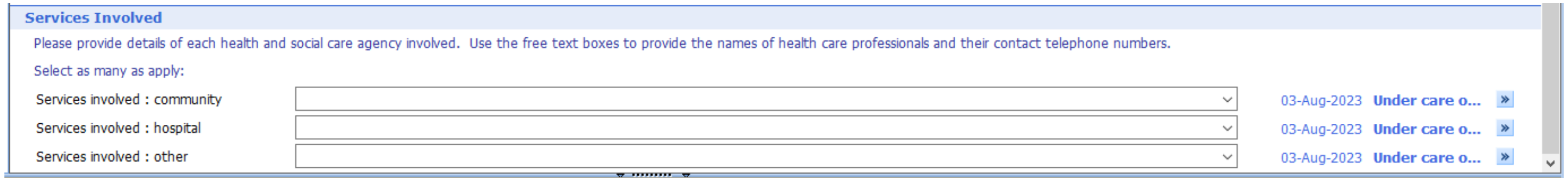
☐ Telecare / careline in place	Text	03-Aug-2023	

Accountable GP

Accountable GP		16-Sep-2015	

Care Co-ordinator

☐ Name of care co-ordinator	Text	03-Aug-2023	



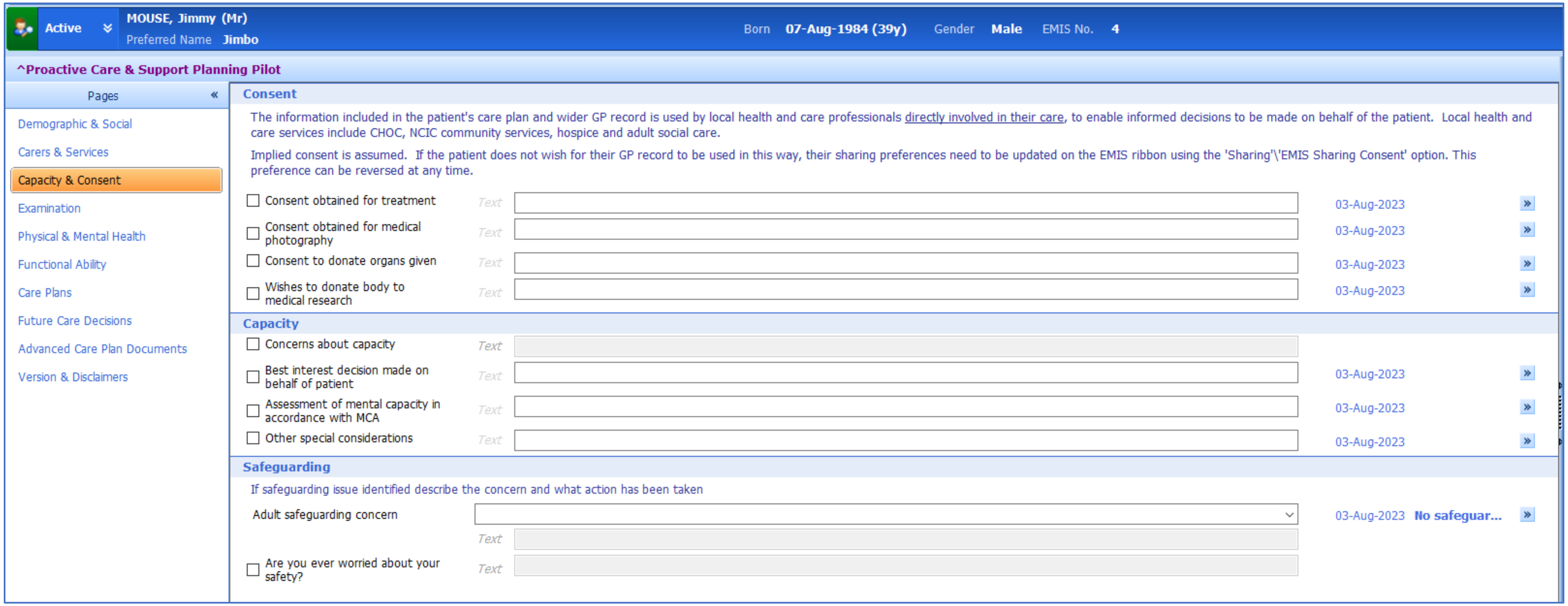
Services Involved

Please provide details of each health and social care agency involved. Use the free text boxes to provide the names of health care professionals and their contact telephone numbers.

Select as many as apply:

Services involved : community	03-Aug-2023	**Under care o...**
Services involved : hospital	03-Aug-2023	**Under care o...**
Services involved : other	03-Aug-2023	**Under care o...**

Capacity & Consent



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Preferred Name **Jimbo**
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Consent

The information included in the patient's care plan and wider GP record is used by local health and care professionals directly involved in their care, to enable informed decisions to be made on behalf of the patient. Local health and care services include CHOC, NCIC community services, hospice and adult social care.

Implied consent is assumed. If the patient does not wish for their GP record to be used in this way, their sharing preferences need to be updated on the EMIS ribbon using the 'Sharing'\'EMIS Sharing Consent' option. This preference can be reversed at any time.

☐ Consent obtained for treatment — Text — 03-Aug-2023
☐ Consent obtained for medical photography — Text — 03-Aug-2023
☐ Consent to donate organs given — Text — 03-Aug-2023
☐ Wishes to donate body to medical research — Text — 03-Aug-2023

Capacity

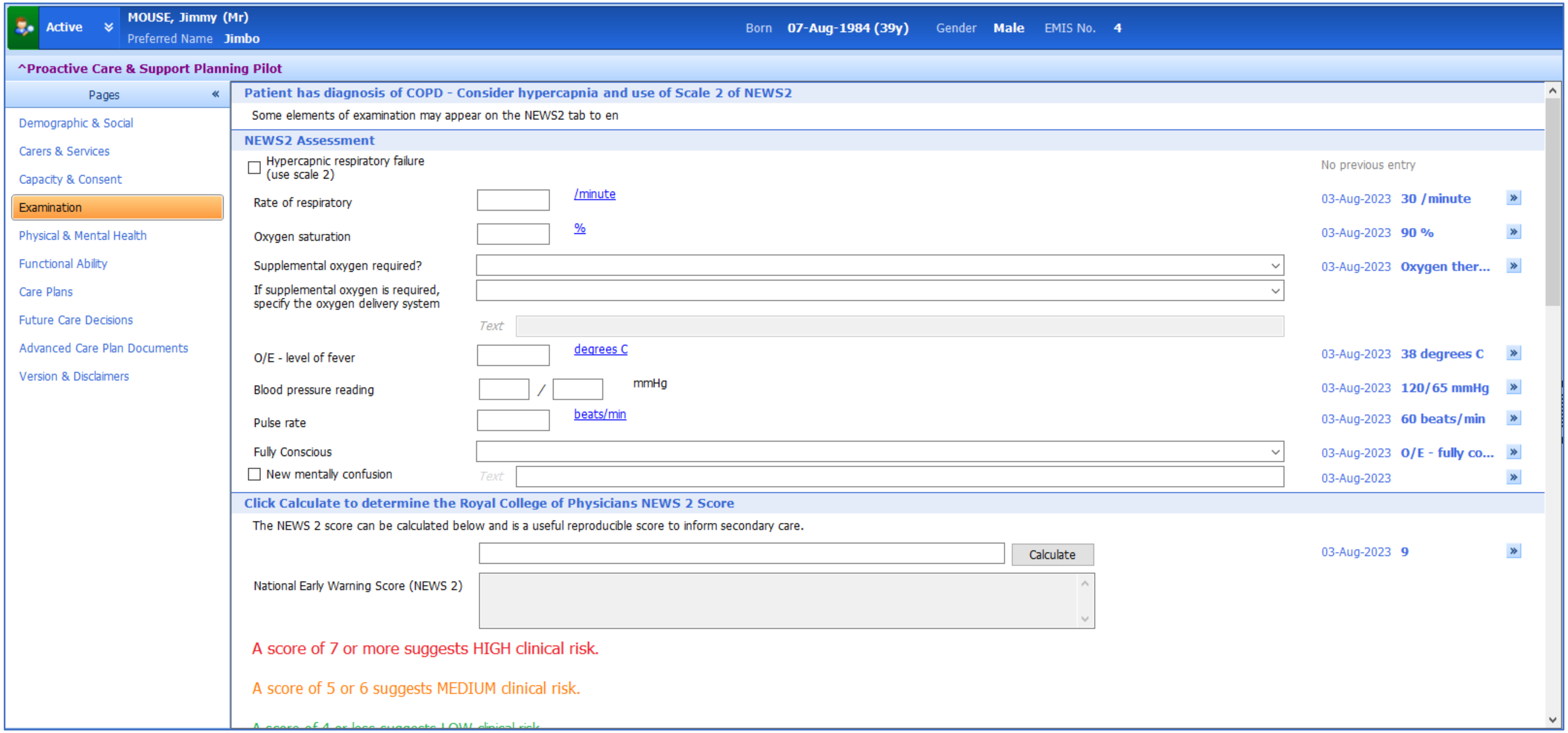
☐ Concerns about capacity — Text
☐ Best interest decision made on behalf of patient — Text — 03-Aug-2023
☐ Assessment of mental capacity in accordance with MCA — Text — 03-Aug-2023
☐ Other special considerations — Text — 03-Aug-2023

Safeguarding

If safeguarding issue identified describe the concern and what action has been taken

Adult safeguarding concern — 03-Aug-2023 **No safeguar...**
Text
☐ Are you ever worried about your safety? — Text

Examination



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Patient has diagnosis of COPD - Consider hypercapnia and use of Scale 2 of NEWS2

Some elements of examination may appear on the NEWS2 tab to en

NEWS2 Assessment

☐ Hypercapnic respiratory failure (use scale 2)		No previous entry
Rate of respiratory	/minute	03-Aug-2023 **30 /minute**
Oxygen saturation	%	03-Aug-2023 **90 %**
Supplemental oxygen required?		03-Aug-2023 **Oxygen ther...**
If supplemental oxygen is required, specify the oxygen delivery system	Text	
O/E - level of fever	degrees C	03-Aug-2023 **38 degrees C**
Blood pressure reading	/ mmHg	03-Aug-2023 **120/65 mmHg**
Pulse rate	beats/min	03-Aug-2023 **60 beats/min**
Fully Conscious		03-Aug-2023 **O/E - fully co...**
☐ New mentally confusion	Text	03-Aug-2023

Click Calculate to determine the Royal College of Physicians NEWS 2 Score

The NEWS 2 score can be calculated below and is a useful reproducible score to inform secondary care.

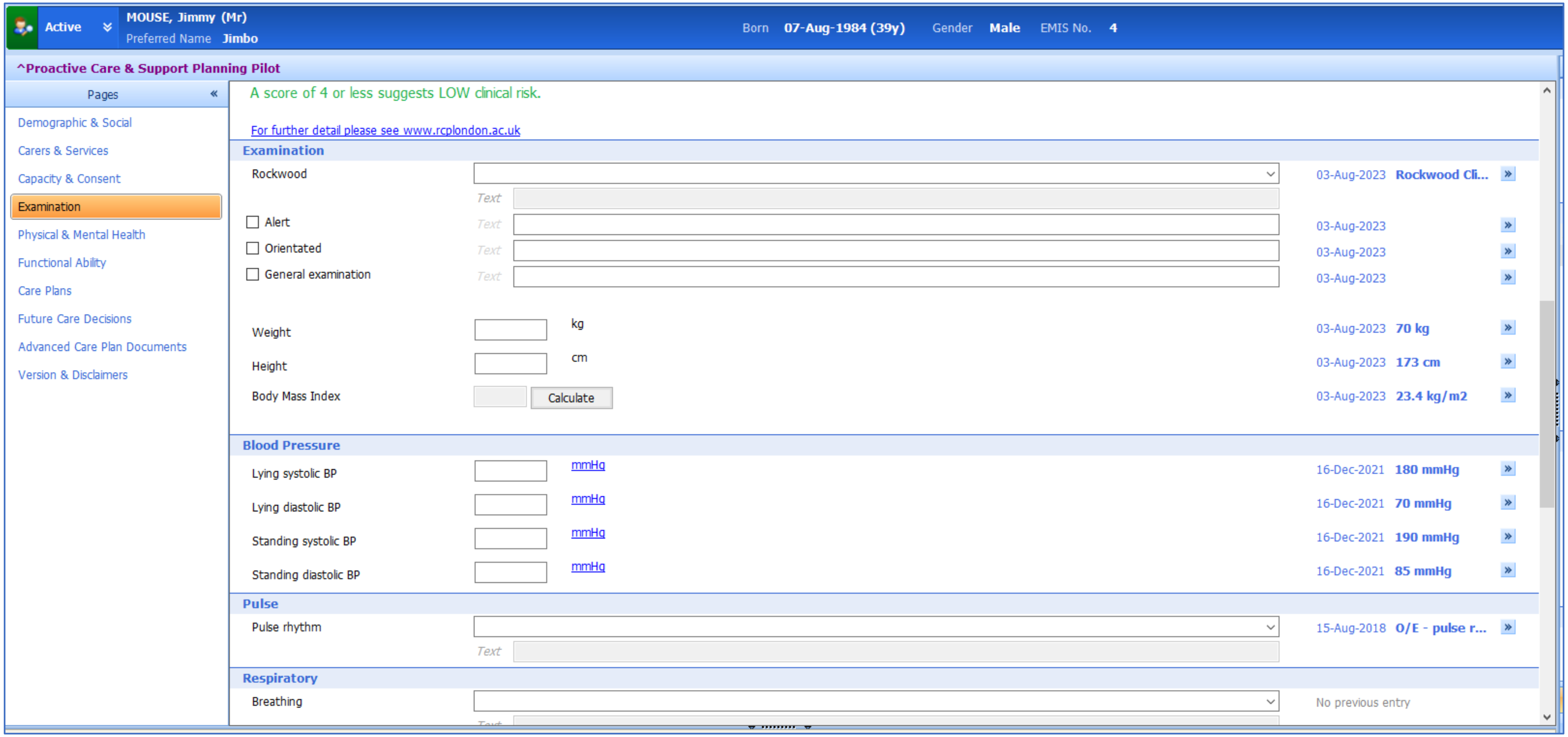
Calculate — 03-Aug-2023 **9**

National Early Warning Score (NEWS 2)

A score of 7 or more suggests HIGH clinical risk.

A score of 5 or 6 suggests MEDIUM clinical risk.

A score of 4 or less suggests LOW clinical risk.



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A score of 4 or less suggests LOW clinical risk.

For further detail please see www.rcplondon.ac.uk

Examination

Rockwood		03-Aug-2023 **Rockwood Cli...**
☐ Alert	Text	03-Aug-2023
☐ Orientated	Text	03-Aug-2023
☐ General examination	Text	03-Aug-2023
Weight	kg	03-Aug-2023 **70 kg**
Height	cm	03-Aug-2023 **173 cm**
Body Mass Index	Calculate	03-Aug-2023 **23.4 kg/m2**

Blood Pressure

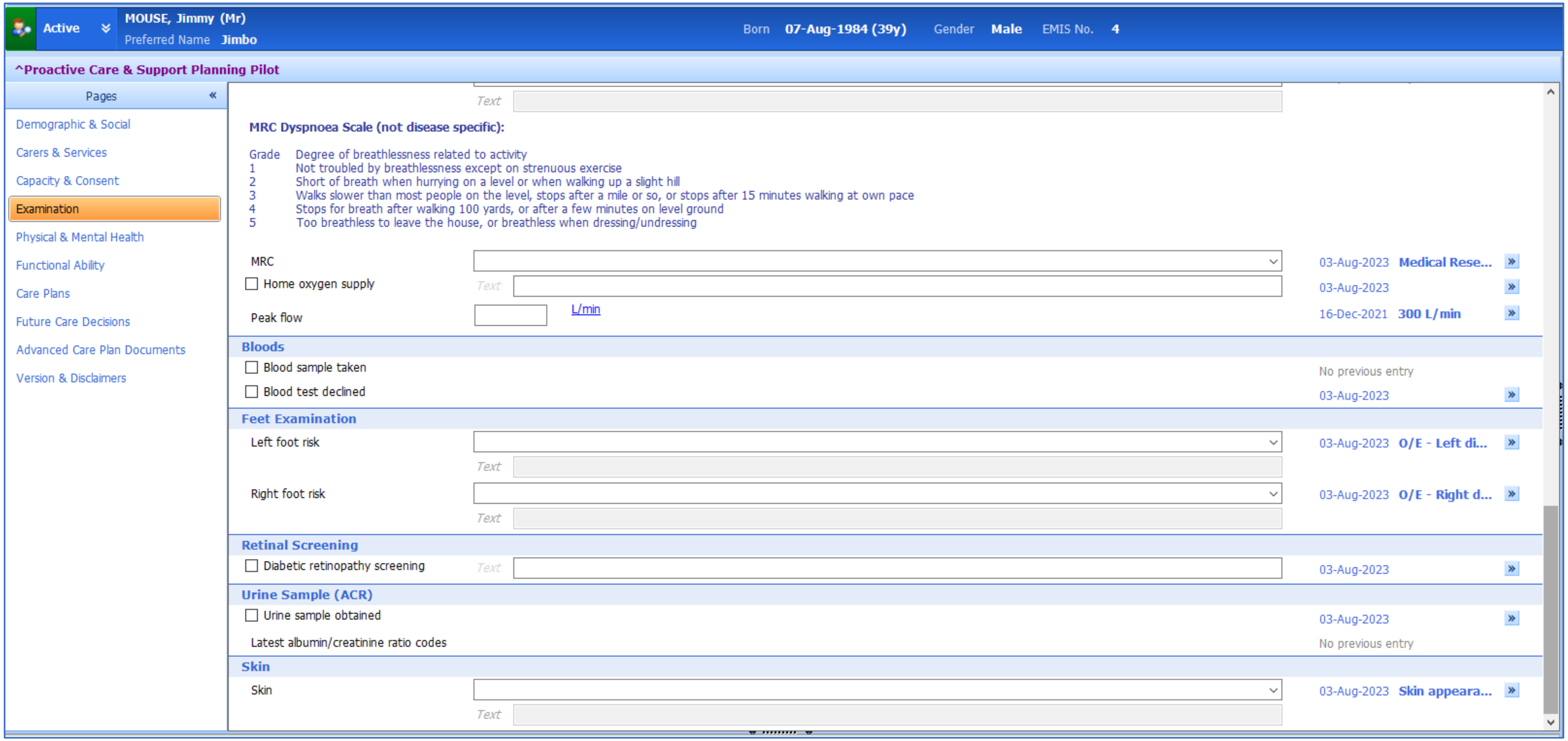
Lying systolic BP	mmHg	16-Dec-2021 **180 mmHg**
Lying diastolic BP	mmHg	16-Dec-2021 **70 mmHg**
Standing systolic BP	mmHg	16-Dec-2021 **190 mmHg**
Standing diastolic BP	mmHg	16-Dec-2021 **85 mmHg**

Pulse

Pulse rhythm	Text	15-Aug-2018 **O/E - pulse r...**

Respiratory

Breathing		No previous entry



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Text

MRC Dyspnoea Scale (not disease specific):

Grade	Degree of breathlessness related to activity
1	Not troubled by breathlessness except on strenuous exercise
2	Short of breath when hurrying on a level or when walking up a slight hill
3	Walks slower than most people on the level, stops after a mile or so, or stops after 15 minutes walking at own pace
4	Stops for breath after walking 100 yards, or after a few minutes on level ground
5	Too breathless to leave the house, or breathless when dressing/undressing

MRC — 03-Aug-2023 **Medical Rese...**
☐ Home oxygen supply — Text — 03-Aug-2023
Peak flow — L/min — 16-Dec-2021 **300 L/min**

Bloods
☐ Blood sample taken — No previous entry
☐ Blood test declined — 03-Aug-2023

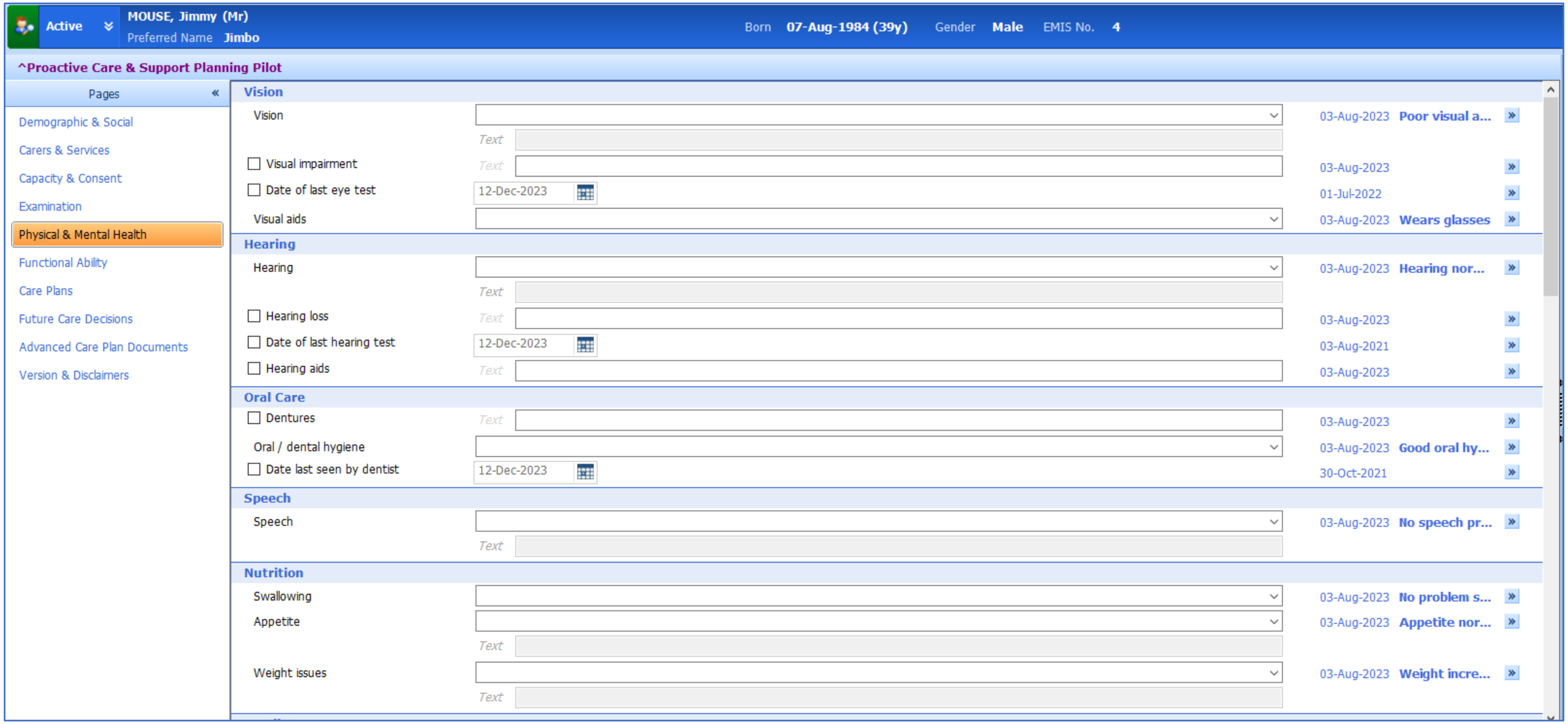
Feet Examination
Left foot risk — 03-Aug-2023 **O/E - Left di...**
Text
Right foot risk — 03-Aug-2023 **O/E - Right d...**
Text

Retinal Screening
☐ Diabetic retinopathy screening — Text — 03-Aug-2023

Urine Sample (ACR)
☐ Urine sample obtained — 03-Aug-2023
Latest albumin/creatinine ratio codes — No previous entry

Skin
Skin — 03-Aug-2023 **Skin appeara...**
Text

Physical & Mental Health



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Vision

Vision — 03-Aug-2023 **Poor visual a...**
Text
☐ Visual impairment — Text — 03-Aug-2023
☐ Date of last eye test — 12-Dec-2023 — 01-Jul-2022
Visual aids — 03-Aug-2023 **Wears glasses**

Hearing

Hearing — 03-Aug-2023 **Hearing nor...**
Text
☐ Hearing loss — Text — 03-Aug-2023
☐ Date of last hearing test — 12-Dec-2023 — 03-Aug-2021
☐ Hearing aids — Text — 03-Aug-2023

Oral Care

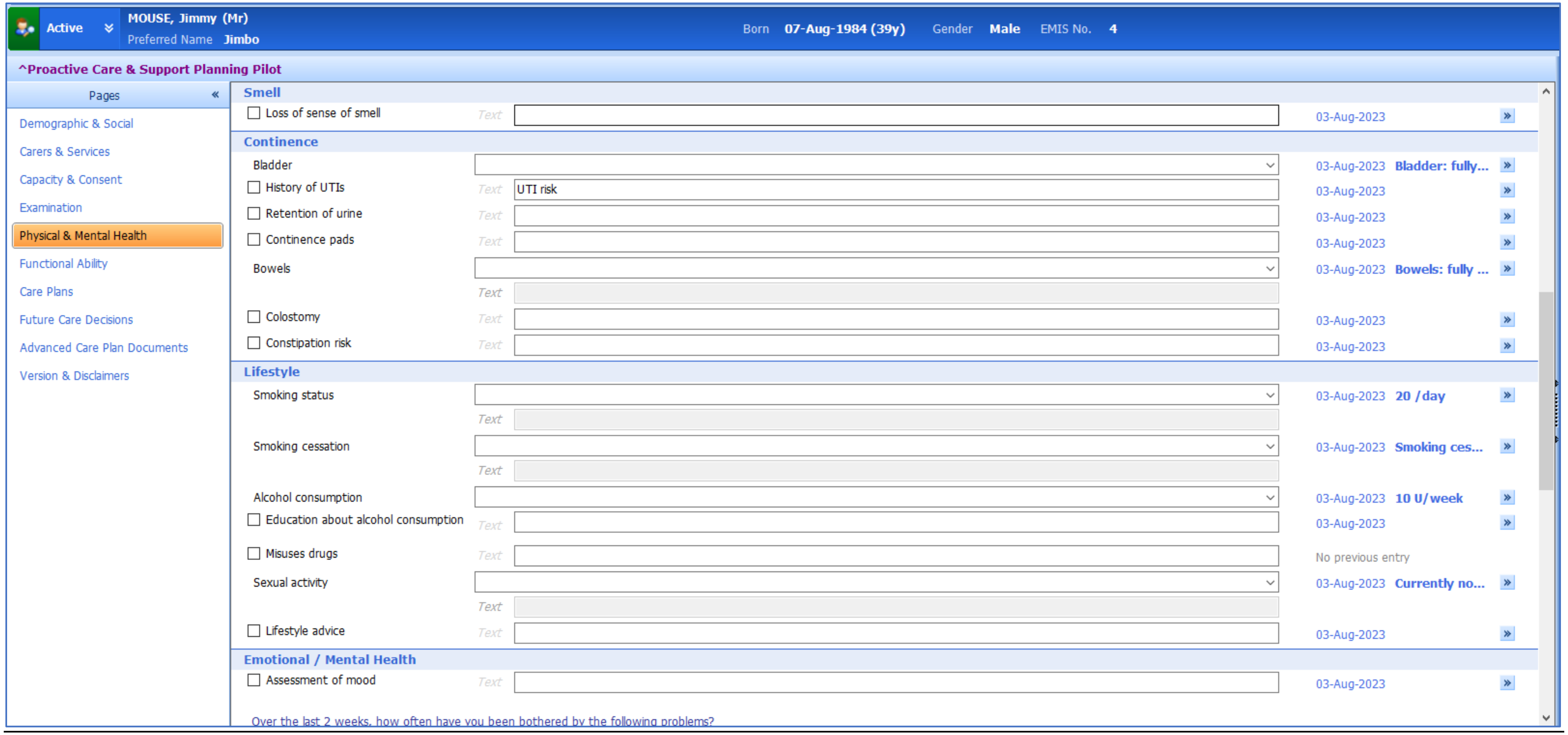
☐ Dentures — Text — 03-Aug-2023
Oral / dental hygiene — 03-Aug-2023 **Good oral hy...**
☐ Date last seen by dentist — 12-Dec-2023 — 30-Oct-2021

Speech

Speech — 03-Aug-2023 **No speech pr...**
Text

Nutrition

Swallowing — 03-Aug-2023 **No problem s...**
Appetite — 03-Aug-2023 **Appetite nor...**
Text
Weight issues — 03-Aug-2023 **Weight incre...**
Text



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Smell

☐ Loss of sense of smell	Text	03-Aug-2023	

Continence

Bladder		03-Aug-2023	**Bladder: fully...**
☐ History of UTIs	UTI risk	03-Aug-2023	
☐ Retention of urine	Text	03-Aug-2023	
☐ Continence pads	Text	03-Aug-2023	
Bowels	Text	03-Aug-2023	**Bowels: fully ...**
☐ Colostomy	Text	03-Aug-2023	
☐ Constipation risk	Text	03-Aug-2023	

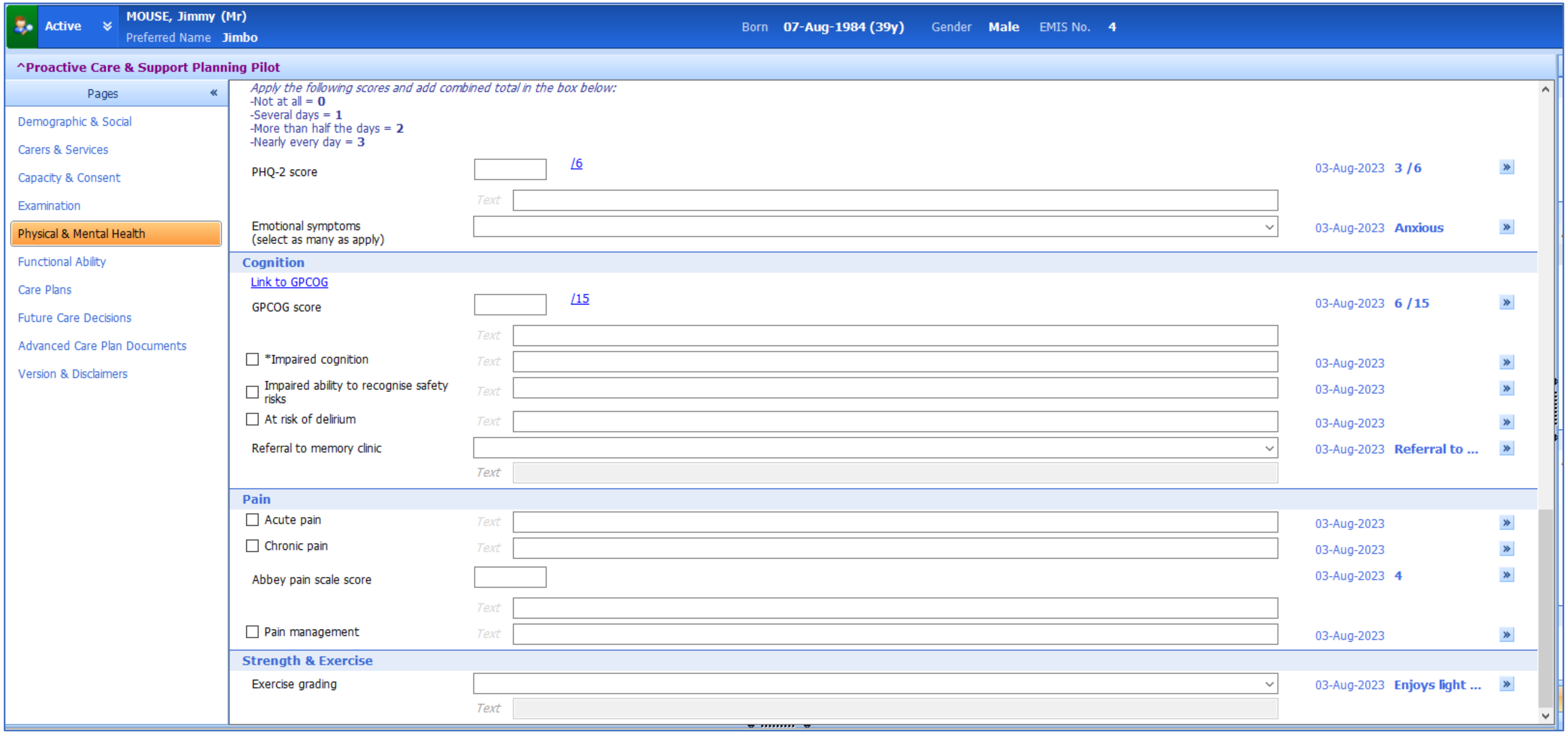
Lifestyle

Smoking status	Text	03-Aug-2023	**20 /day**
Smoking cessation	Text	03-Aug-2023	**Smoking ces...**
Alcohol consumption		03-Aug-2023	**10 U/week**
☐ Education about alcohol consumption	Text	03-Aug-2023	
☐ Misuses drugs	Text	No previous entry	
Sexual activity	Text	03-Aug-2023	**Currently no...**
☐ Lifestyle advice	Text	03-Aug-2023	

Emotional / Mental Health

☐ Assessment of mood	Text	03-Aug-2023	

Over the last 2 weeks, how often have you been bothered by the following problems?



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Pages

- Demographic & Social
- Carers & Services
- Capacity & Consent
- Examination
- Physical & Mental Health
- Functional Ability
- Care Plans
- Future Care Decisions
- Advanced Care Plan Documents
- Version & Disclaimers

Apply the following scores and add combined total in the box below:

-Not at all = **0**
-Several days = **1**
-More than half the days = **2**
-Nearly every day = **3**

PHQ-2 score /6 — 03-Aug-2023 **3 / 6**

Text

Emotional symptoms (select as many as apply) — 03-Aug-2023 **Anxious**

Cognition

Link to GPCOG

GPCOG score /15 — 03-Aug-2023 **6 / 15**

Text

☐ *Impaired cognition — Text — 03-Aug-2023

☐ Impaired ability to recognise safety risks — Text — 03-Aug-2023

☐ At risk of delirium — Text — 03-Aug-2023

Referral to memory clinic — 03-Aug-2023 **Referral to ...**

Text

Pain

☐ Acute pain — Text — 03-Aug-2023

☐ Chronic pain — Text — 03-Aug-2023

Abbey pain scale score — 03-Aug-2023 **4**

Text

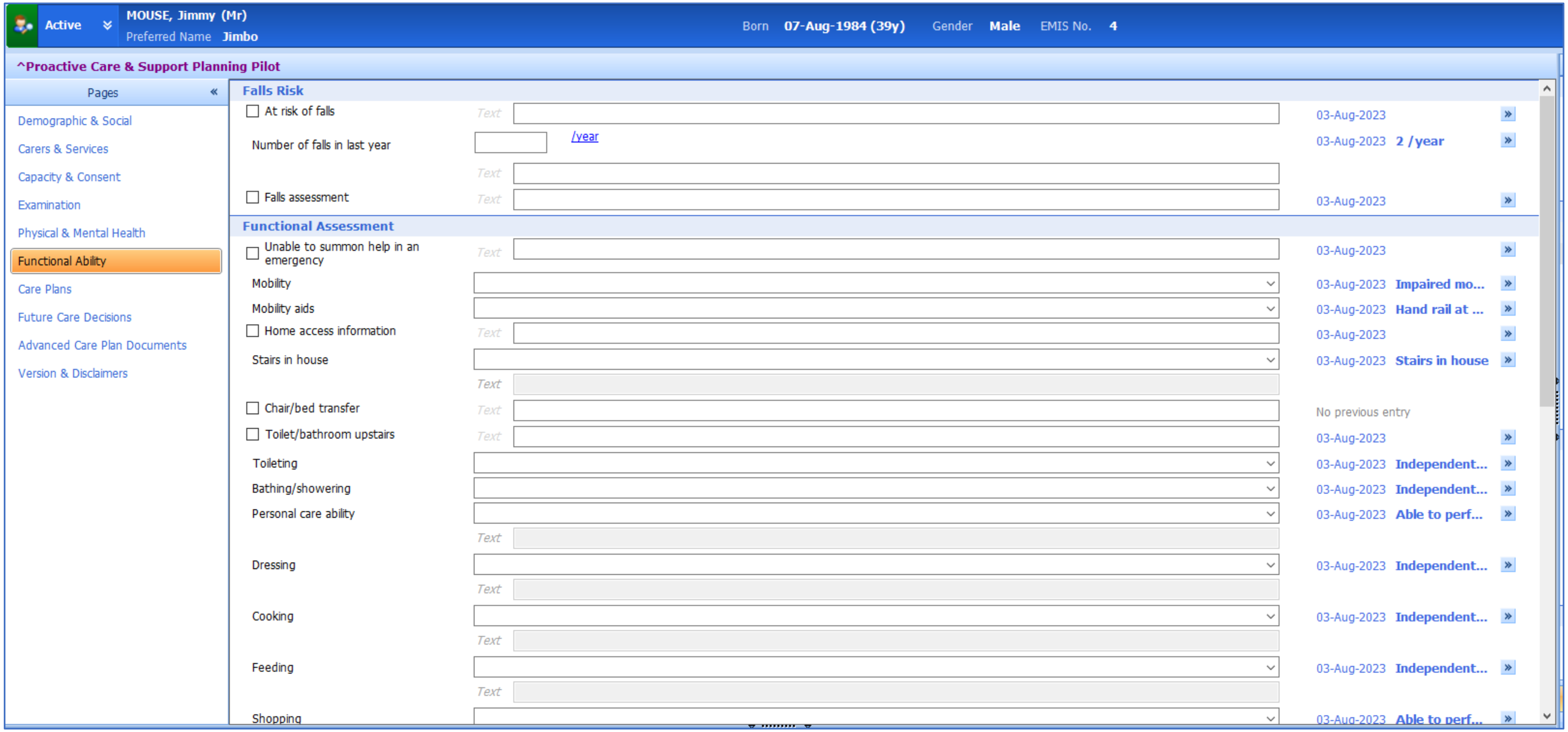
☐ Pain management — Text — 03-Aug-2023

Strength & Exercise

Exercise grading — 03-Aug-2023 **Enjoys light ...**

Text

Functional Ability



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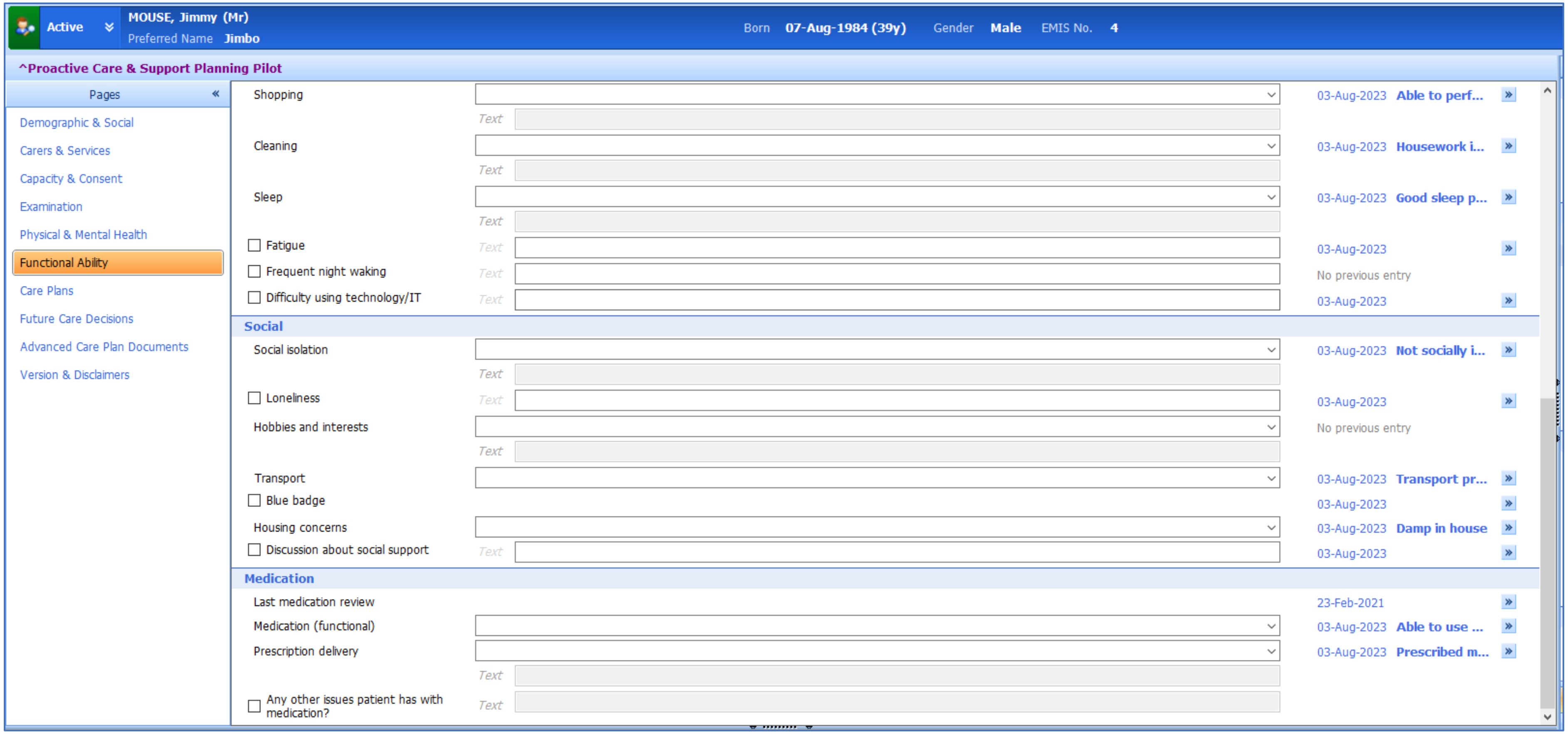
Falls Risk

☐ At risk of falls	Text	03-Aug-2023	
Number of falls in last year	/year	03-Aug-2023	**2 /year**
	Text		
☐ Falls assessment	Text	03-Aug-2023	

Functional Assessment

☐ Unable to summon help in an emergency	Text	03-Aug-2023	
Mobility		03-Aug-2023	**Impaired mo...**
Mobility aids		03-Aug-2023	**Hand rail at ...**
☐ Home access information	Text	03-Aug-2023	
Stairs in house		03-Aug-2023	**Stairs in house**
	Text		
☐ Chair/bed transfer	Text	No previous entry	
☐ Toilet/bathroom upstairs	Text	03-Aug-2023	
Toileting		03-Aug-2023	**Independent...**
Bathing/showering		03-Aug-2023	**Independent...**
Personal care ability		03-Aug-2023	**Able to perf...**
	Text		
Dressing		03-Aug-2023	**Independent...**
	Text		
Cooking		03-Aug-2023	**Independent...**
	Text		
Feeding		03-Aug-2023	**Independent...**
	Text		
Shopping		03-Aug-2023	**Able to perf...**



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Shopping		03-Aug-2023	**Able to perf...**
	Text		
Cleaning		03-Aug-2023	**Housework i...**
	Text		
Sleep		03-Aug-2023	**Good sleep p...**
	Text		
☐ Fatigue	Text	03-Aug-2023	
☐ Frequent night waking	Text	No previous entry	
☐ Difficulty using technology/IT	Text	03-Aug-2023	

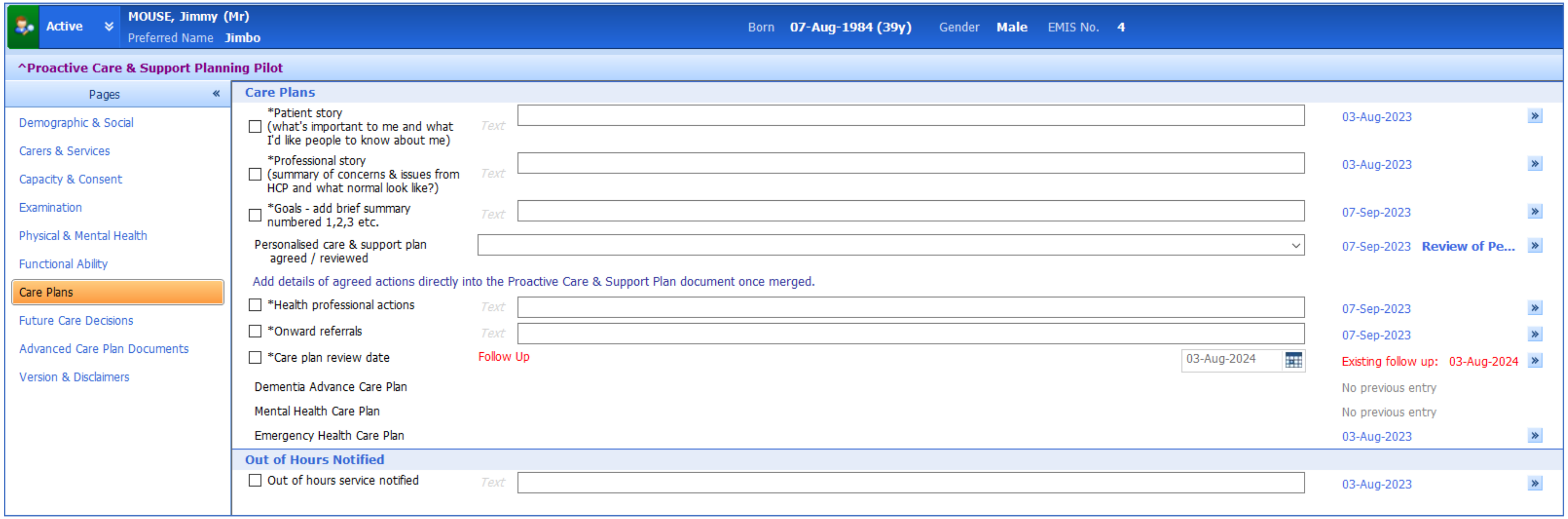
Social

Social isolation		03-Aug-2023	**Not socially i...**
	Text		
☐ Loneliness	Text	03-Aug-2023	
Hobbies and interests		No previous entry	
	Text		
Transport		03-Aug-2023	**Transport pr...**
☐ Blue badge		03-Aug-2023	
Housing concerns		03-Aug-2023	**Damp in house**
☐ Discussion about social support	Text	03-Aug-2023	

Medication

Last medication review		23-Feb-2021	
Medication (functional)		03-Aug-2023	**Able to use ...**
Prescription delivery		03-Aug-2023	**Prescribed m...**
	Text		
☐ Any other issues patient has with medication?	Text		

Care Plans



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Care Plans

☐ *Patient story (what's important to me and what I'd like people to know about me) Text 03-Aug-2023

☐ *Professional story (summary of concerns & issues from HCP and what normal look like?) Text 03-Aug-2023

☐ *Goals - add brief summary numbered 1,2,3 etc. Text 07-Sep-2023

Personalised care & support plan agreed / reviewed 07-Sep-2023 **Review of Pe...**

Add details of agreed actions directly into the Proactive Care & Support Plan document once merged.

☐ *Health professional actions Text 07-Sep-2023

☐ *Onward referrals Text 07-Sep-2023

☐ *Care plan review date Follow Up 03-Aug-2024 Existing follow up: 03-Aug-2024

Dementia Advance Care Plan No previous entry

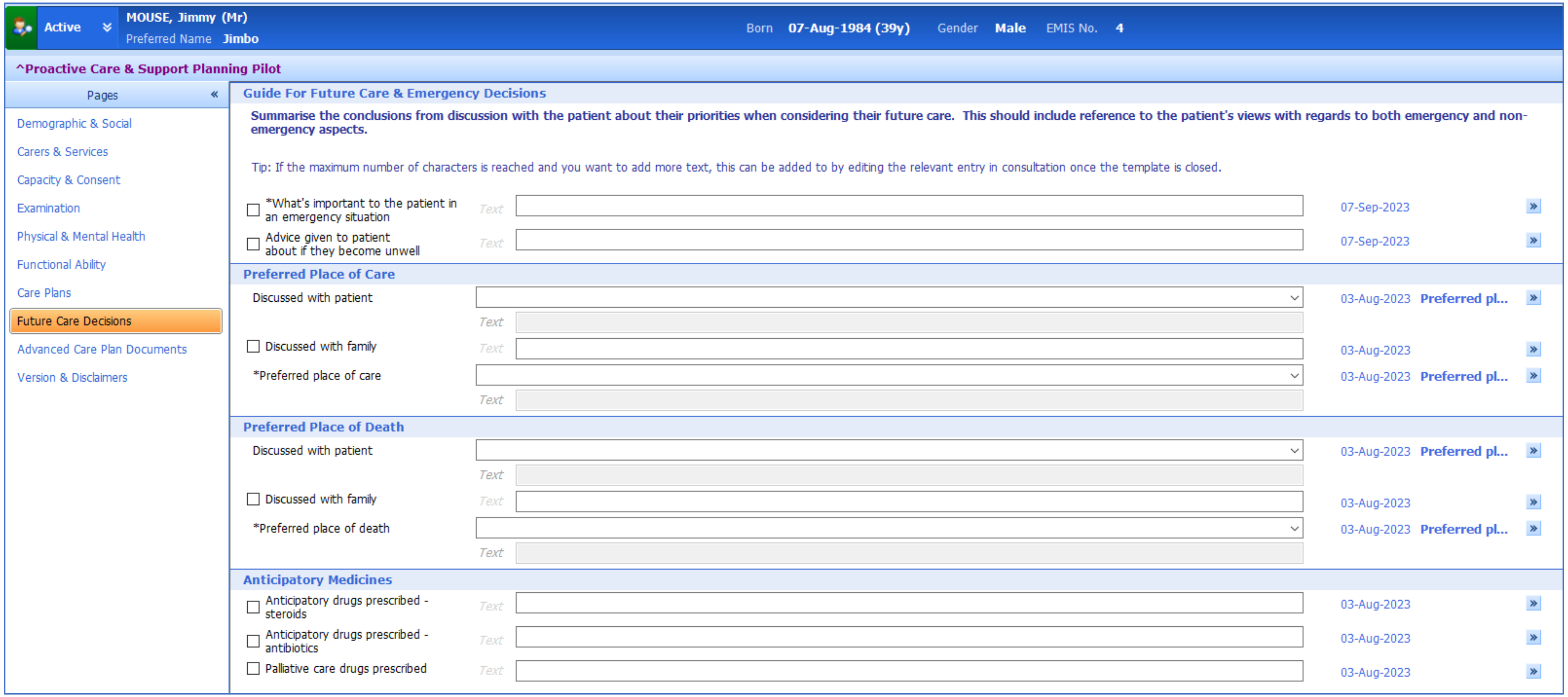
Mental Health Care Plan No previous entry

Emergency Health Care Plan 03-Aug-2023

Out of Hours Notified

☐ Out of hours service notified Text 03-Aug-2023

Future Care Decisions



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Guide For Future Care & Emergency Decisions

Summarise the conclusions from discussion with the patient about their priorities when considering their future care. This should include reference to the patient's views with regards to both emergency and non-emergency aspects.

Tip: If the maximum number of characters is reached and you want to add more text, this can be added to by editing the relevant entry in consultation once the template is closed.

☐ *What's important to the patient in an emergency situation — Text — 07-Sep-2023
☐ Advice given to patient about if they become unwell — Text — 07-Sep-2023

Preferred Place of Care

Discussed with patient — 03-Aug-2023 **Preferred pl...**
Text
☐ Discussed with family — Text — 03-Aug-2023
*Preferred place of care — 03-Aug-2023 **Preferred pl...**
Text

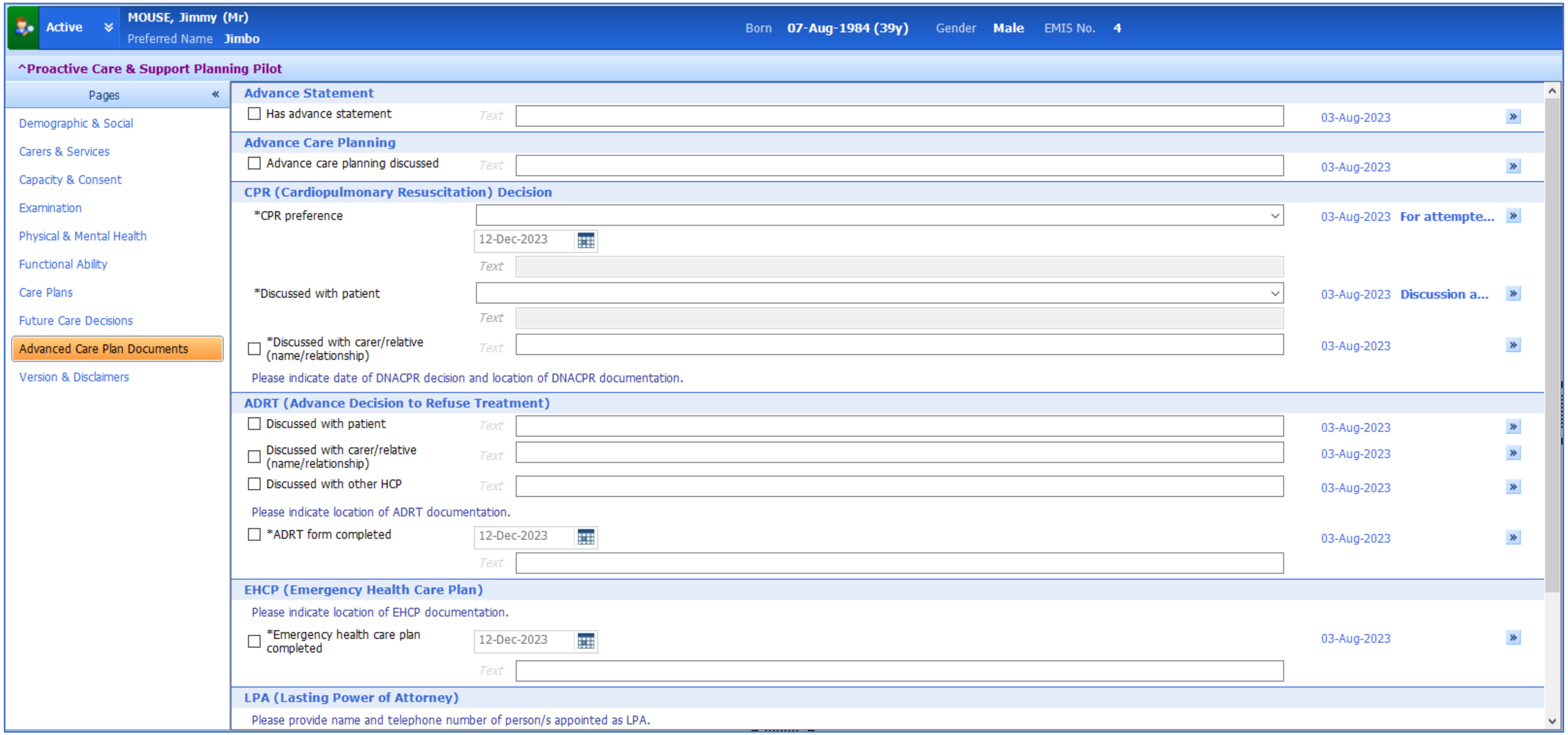
Preferred Place of Death

Discussed with patient — 03-Aug-2023 **Preferred pl...**
Text
☐ Discussed with family — Text — 03-Aug-2023
*Preferred place of death — 03-Aug-2023 **Preferred pl...**
Text

Anticipatory Medicines

☐ Anticipatory drugs prescribed - steroids — Text — 03-Aug-2023
☐ Anticipatory drugs prescribed - antibiotics — Text — 03-Aug-2023
☐ Palliative care drugs prescribed — Text — 03-Aug-2023

Advanced Care Plan Documents



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Advance Statement

☐ Has advance statement Text 03-Aug-2023

Advance Care Planning

☐ Advance care planning discussed Text 03-Aug-2023

CPR (Cardiopulmonary Resuscitation) Decision

*CPR preference 03-Aug-2023 **For attempte...**
12-Dec-2023
Text

*Discussed with patient 03-Aug-2023 **Discussion a...**
Text

☐ *Discussed with carer/relative (name/relationship) Text 03-Aug-2023

Please indicate date of DNACPR decision and location of DNACPR documentation.

ADRT (Advance Decision to Refuse Treatment)

☐ Discussed with patient Text 03-Aug-2023
☐ Discussed with carer/relative (name/relationship) Text 03-Aug-2023
☐ Discussed with other HCP Text 03-Aug-2023

Please indicate location of ADRT documentation.

☐ *ADRT form completed 12-Dec-2023 03-Aug-2023
Text

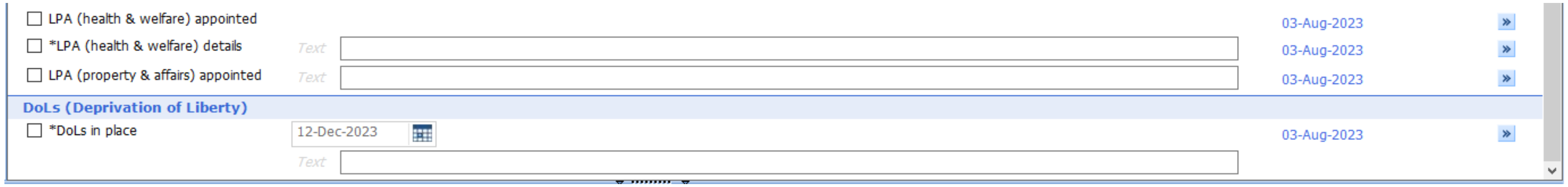
EHCP (Emergency Health Care Plan)

Please indicate location of EHCP documentation.

☐ *Emergency health care plan completed 12-Dec-2023 03-Aug-2023
Text

LPA (Lasting Power of Attorney)

Please provide name and telephone number of person/s appointed as LPA.



☐ LPA (health & welfare) appointed 03-Aug-2023
☐ *LPA (health & welfare) details Text 03-Aug-2023
☐ LPA (property & affairs) appointed Text 03-Aug-2023

DoLs (Deprivation of Liberty)

☐ *DoLs in place 12-Dec-2023 03-Aug-2023
Text

Appendix 7 – Patient preparation materials

The Very Person Centred Medical Group
Self-Care Place
Welltown

Date XXX

Dear XXX

We would like to invite you to have a review with our care coordinator and healthcare team.

Your first appointment is arranged for XXX practice or in your home on date at time and will be with XXXXXXXXX.

What does this mean for you?
We hope this review will ensure that

- all your health conditions are reviewed together
- you get the advice and support you need to stay well based on what is most important to you
- your preferences about your future care are recorded in your healthcare record

We will work with you to produce a plan to help you manage your health and care needs.

There may be 1 or 2 appointments and they will usually last a maximum of 1 hour.

What happens at the first appointment?

- We will start the conversation by finding out about you and what matters to you
- If you have conditions such as heart disease, diabetes or breathing problems the care coordinator will also complete important tests and assessments as part of this review

To help with this it would be helpful if you could complete the enclosed form.

If you prefer, please have a friend or family member with you.

Your GP

Enclosed:
Things that are bothering me

Preparing for Care Planning

Your care planning appointment is for you to think about what is important to you, things you can do to live well and stay well, and what care and support you might need to do this.

This letter contains some of your test results and information, along with some questions, to help you think ahead and plan what you would like to discuss at your appointment.

Please bring this to your appointment. The back page will be used to record the summary and the plans you make.

What are the most important things to you at the moment?

These are some things that people sometimes want to talk about. Circle any that are important to you.

Bathing and hygiene	My current care	Looking after family, carers and pets	Support to stay at home
Finances	Independence	Getting out and about	Pain
Feeling low or anxious	Feeling scared	Feeling hopeless	Mobility
Medication	My future health	Eating and drinking	Loneliness
Keeping warm	My memory	Hearing	Smoking
Staying steady	My weight	Slowing down	My sight

What else would you like to discuss?

Things that are bothering me…

Name	**Completed with**
Date	

This tool is to help you, and your family and carers, think about how things are working for you at the moment and help your health and care team understand more about the kinds of support you need. Please complete it to identify any concerns, things that matter to you and any issues you want to discuss at your appointment.

Activities of daily living	Not a problem	Causes me concern
Bathing and washing		
Getting dressed		
Going to the toilet		
Preparing a meal		
Shopping		
Eating and drinking		
Doing housework		
Using the telephone		
Remembering things		
Driving		

Physical health	Not a problem	Causes me concern
Being able to see things		
Being able to hear things		
Being able to go outside (with or without help)		
Being steady on your feet		
Getting around your home		
Getting out to social activities		
Falls – how many in the last year?		
Slowing down		
Keeping warm		
Coping with pain		
Losing weight without dieting		
Sleeping		
Continence		
Constipation		

Thoughts and feelings	Not a problem	Causes me concern
Feeling down and depressed		
Feeling tired		
Feeling anxious		
Feeling lonely		
Worrying about the future		

Care and support	No	Yes
Do you live on your own?		
Do you have a relative or carer helping you regularly at home?		
Would you like more support?		
Are you receiving services, treatment or support you no longer need or want?		
Are you a carer?		
Do you feel your housing is a problem?		
Do you want advice on work or volunteering?		
Do you need support with benefits or finance?		

Lifestyle	Not a problem	Causes me concern
Hobbies and interests		
Wanting to lose weight		
Smoking (how many cigarettes each day…………)		
Relationships (e.g., companionship/ sex life)		
Alcohol consumption		
Being active		

Health care	Not a problem	Causes me concern
Attending appointments		
Knowing who to contact		
Knowing what to do if things get worse		
Your medications		

Any other comments or questions

Appendix 8 – Finding the Words

Invitation and Explanation for Proactive Care

‘Finding the Words’

Top Tips

As the proactive care pilot programme developed it became clear that proactive care teams needed to carefully consider how they approached people about the offer of personalised care and support planning, and that not all people would welcome this.

We explored some of the perceptions and intricacies around language, particularly around the first phone call to patients. First impressions are important!

Here are some of the ideas that were developed about the words that might be used:

Say who you are:

- Introduce yourself
- Explain you are from the person’s GP surgery and that you are working with their local GP

Let people know how they have been identified:

- Help people see that you have ‘done your homework’ and understand the complex care they must navigate, *“we have noticed you have been having to come to the see the GP/nurses a lot/ attending A&E recently/ been in hospital and wanted to see if we could try and join things up a bit better”*.
- *“Your GP thinks it might be of benefit to you”.*

Making it personalised with words such as:

- A chance to explore how things are with your health and what could make a difference to you.
- An opportunity for us to listen to your concerns/what’s important to you/what matters to you.
- An opportunity to think about your health and how you can stay well at home.
- Time to think about how we could support you differently.
- Offer support to join up or coordinate your care and make sure nothing has been missed.
- As part of the process, we will make sure you have had all your bloods done and ask you and your GP to check your medicines.
- We are offering to come and see you at home and spend a bit of time looking at things with you.

Make sure that:

- People know they can have a friend or relative with them.
- People know they are going to be sent a preparation prompt to help them identify the topics they want to discuss.
- They know when you are coming, what you plan to do and how long it will take.

Appendix 9 – Role outline for care coordinators in relation to role in proactive care

Domain – administration and coordination

- Able to run searches and identify people who would benefit from anticipatory/proactive care
- Overseeing the invitation of patients into the programme
- Adding/updating basic demographic details in clinical record
- Diary keeping and coordination of team appointments
- Accurate data entry and, where required, production of personalised care and support plans
- Linking with other members of the MDT (referral or support as and when required)
- Coordinating MDT meetings and taking notes/actions

Domain – information gathering (communication and personalised care)

- Philosophically in tune with the values and ethos of a personalised approach to care
- Takes a biopsychosocial approach and sees people holistically
- Understands the value of using the person's life story to inform care
- Use of person-centred communication approaches including coaching, shared decision making and personalised support planning (non-judgemental and proactive)
- Able to listen to the patient narrative and discover the preferences and priorities of the individual
- Able to involve families/ carers appropriately and value their input
- Able to identify individuals who wish to work with a qualified professional to create advance care plans and emergency care plans

Domain – information gathering (physical tests and assessments)

Basic understanding of different LTC's and key red flags/able to identify deterioration

Physical tests and tasks (appropriate to LTC and patient)

- Height and weight
- BP (including standing and lying BP)
- Pulse (rate and rhythm)
- Check vaccination status
- Check if attended retinal screening (if needed)
- Phlebotomy
- ACR and detection of UTI
- CAT and MRC scores
- Oxygen sats/peak flow
- Foot assessment (circulation and sensation)

General assessments

- Assess smoking status and drug/alcohol consumption
- Medication - able to assess basic concordance/identify issues associated with medicines from patient's point of view. Is aware of side effects of common medications and understands the importance of regular review (with supervision from prescriber).
- Uses effective communication skills and appropriate screening tools to identify common physical health issues including:
    - pain

  - continence
  - falls
  - nutrition and hydration
  - skin health
  - sensory loss (vision, hearing, sense of smell)
  - oral health
- Uses effective communication skills and appropriate screening tools to identify common mental health issues including:
  - mood/anxiety
  - cognitive impairment (including basic mental capacity assessment)
  - delirium

Frailty

- Aware of eFI and able to clinically validate frailty (using Rockwood tool)
- Recognises the physical characteristics and progression of frailty and how it impacts on older people
- Knowledge of interventions and opportunities that can prevent or slow the progression of frailty
- Aware of the 5 frailty syndromes and how these can often present as the first sign of illness in those living with frailty
- Awareness of the ways in which falls can be prevented and managed
- Ability to undertake basic functional assessment including mobility/transfers/personal care - may include standardised measures
- Ability to undertake basic environmental risk assessment
- Supports positive risk taking for independence and wellbeing
- Understands impact of social isolation and loneliness; feels confident to explore this with patients
- Aware of NEWS2, the meaning of scores and the local process to escalate appropriately

Domain – social prescribing and care coordination (signposting and access to community activities)

- Understands roles within multidisciplinary team and who to approach for support, advice, and direct patient contact
- Referral or prescription of basic aids/equipment
- Signposting to universal services such as CAB, Age UK etc.
- Supporting applications for e.g. attendance allowance
- Able to access and signpost to a range of community-based activities for patients and carers
- Links to/awareness of local housing providers/telecare and referral routes
- Aware of carer support and availability, or carer reviews

Appendix 10 – Patient held record of care plan

PERSONALISED PLAN AND EMERGENCY CARE PLAN FOR

XXXXXXXXXXX

The information included in this care plan is correct as XXXXX and should be used as a guide thereafter in your clinical assessment. If any significant changes develop after this date, please discuss with the relevant health professional involved in your care.

The purpose of this document is to give you the opportunity to let your doctor and health care team know about your priorities and preferences for your healthcare *and* how you would choose to be looked after in the future.

- The first section is helpful should an emergency ever happen.
- The second section records your own plans for living with your health conditions.

Please keep this document somewhere prominent in your house for use in an emergency.

IF YOU ARE UNWELL AND NEED ADVICE OR SUPPORT

If you are unwell	
During office hours GP practice	
Out of hours contact CHoC direct	

For any other queries, advice or support (during office hours)	

In an emergency who would you like us to contact?

Name	**Contact number**
Emergency contact	
Next of Kin (if different)	
Carer details (if appropriate)	

KEY INFORMATION SUMMARY

WHAT YOU WOULD LIKE PEOPLE TO KNOW ABOUT YOU

WHAT IS IMPORTANT TO YOU IN AN EMERGENCY SITUATION

SUMMARY FROM GP RECORD

ALLERGIES

MEDICAL SUMMARY (including what normal looks like)

EMERGENCY CARE PLAN

INFORMATION FOR PROFESSIONALS

Full name: **Known as:**	**NHS number**: **Date of birth**:
Telephone numbers: Home: Mobile: Work:	**Key safe/door access code**:
Communication needs:	
Language:	**Interpreter needed:**
Dependants:	**Pets:**
Capacity:	
GP Practice:	

GUIDE FOR FUTURE CARE & EMERGENCY DECISIONS

DNACPR:	
CPR discussed:	
LPA (Health & Welfare):	
Deprivation of Liberty (DoLs) in place:	
Advanced Decision to Refuse Treatment (ADRT):	
Emergency Health Care Plan (EHCP):	
Preferred place of care:	
On palliative care register:	

WHAT TO DO IF YOUR HEALTH SUDDENLY GETS WORSE

Health issue:
What symptoms or changes should you look for?
What actions do you take?
Contact person and number if you need this:

Health issue:
What symptoms or changes should you look for?
What actions do you take?
Contact person and number if you need this:

PERSONAL PLAN

What issues are important to me or what I want to work on:

Personal plan

What my key professional contact will organise for me:
Referral made to:

My plan was completed with:	Review of plan:

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