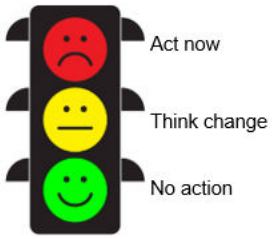
Personalised Care Projects

Final Report Summary 2023



Introduction

In 2021, the QNI - supported by NHS England and Improvement - offered project funding and a programme of development for projects that sought to improve personalised care for people led by community and primary care nurses in England.

Personalised Care describes a way of working that enables individuals and clinicians to work together to deliver care that is realistic, sustainable and appropriate. It means that people have a choice and control over the way that their care is planned and delivered.

The QNI has a long track record of supporting nurses to develop and implement their own ideas to improve the nursing care of the people they care for in the community. Project leaders receive a year-long programme of individual and group support, as well as funding to implement their project to improve healthcare.

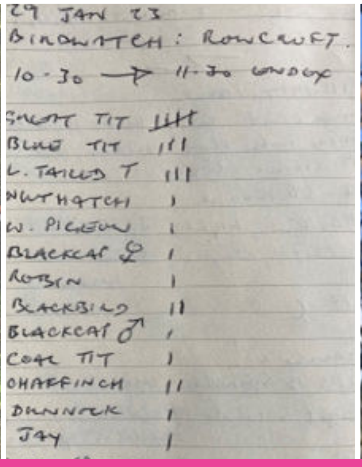
The programme was open to all nurses working in the community and the successful projects were based in across England from Newcastle-upon-Tyne to Cornwall.

The following is a summary of their final reports.

Contents

Rowcroft Space for Nature project

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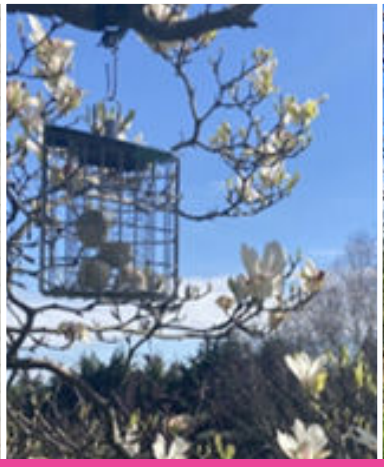
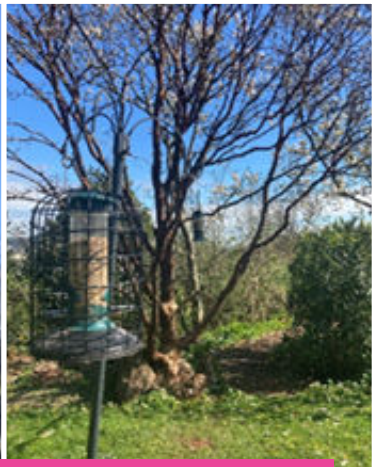



Above: top left: making the pinch pots; top right: some of the art; bottom left: the bird hide; bottom middle: a record of the visiting birds; bottom left: the bird feeders.

Project lead

Sarah Baker, Clinical Nurse Specialist, Devon

Summary

Rowcroft Hospice has extensive gardens and a disused outbuilding was ideally placed to become an outdoor space for patients and relatives. The benefits of connecting with the natural environment can help the emotional and physical challenges faced by those with a life limiting illness, as well as providing an environment that can be utilised for activities for patients, their families and the bereaved.

The bird hide was completed in October 2022. Activities were held in the garden while the bird hide was being renovated; four or five bereaved relatives met weekly and found time in the garden very beneficial.

Two of the group members were able to play musical instruments but both admitted in the music session that since their bereavement they had been unable to play any music. Both people fully participated in the music session and one of them felt able to play a solo guitar piece to the group. On leaving Mr D commented how powerful and emotional he had found the session and was pleased to have played the guitar again for the first time since his bereavement. Mrs K has found a renewed interest in the birds and the natural environment around her, and has told us she is now taking pleasure from being mindful on her walks and spending more time in nature than previously.

‘This project has been a lifeline to me, providing much appreciated support . . .and the incentive to get out of the house to meet with other people.’

An additional session was added at the request of the group for a history walk and presentation by a member of our Estates team, explaining the history and background of the Hospice and grounds.

At the end of the first programme of eight sessions the participants were given a feedback form to measure outcomes. All four of the regular participants completed the feedback form, and the findings are summarised below. In addition to this, participants gave feedback on individual sessions verbally or via email.

None of the group were known to each other at the beginning of the programme, and over the weeks the relationship between them was observed to develop. They were respectful of each other’s feelings and opinions and all members of the group participated in group activities and discussions. In feedback they stated the groups were friendly, interesting, and enjoyable. They enjoyed the opportunity to come to the Hospice gardens.

Participants commented that the group gave them the chance to meet with others experiencing loss and bereavement and helped to combat their loneliness.

Patient Quotes

Mrs R commented *‘This project has been a lifeline to me, providing much appreciated support . . . and the incentive to get out of the house to meet with other people’.*

Mrs M stated that the project ‘survive life’s tests and taught (us) how to start living’. She went on to write the group ‘offered structure and togetherness and gave a good feeling of a place I can attend and feel I belong’.

Mr J commented the group offered the chance to meet new people, have new experiences and combat his ‘profound loneliness’. He started the programme by saying he did not walk for pleasure, only to get from A to B, and he had never walked to appreciate nature. Through the various sessions Mr J began to display an interest in walking in nature for enjoyment and we were able to sign post him to a walking group in his village, which he has gone on to join.

Outstanding achievements

The bird hide has been transformed from an undervalued storage hut to a pleasant useable space for both service users and staff to benefit from.

The bird feeders are very popular with the birds with a wide array of birds visiting the feeders each day.

A volunteer carried out the RSPB Big Garden Birdwatch in January 2022, where he recorded 14 different varieties of bird seen from the Bird Hide in the space of one hour.

Working on the project has encouraged involvement and links with many members of Rowcroft multi-disciplinary team, with joint working established between volunteers, Spiritual Care Team, Complimentary Therapy, music, and art therapy. In the current programme a volunteer with the spiritual care team has committed to supporting each session.

Professional achievements

Increased confidence in group facilitation, with support from colleagues, especially working with bereaved relatives in a way that was not done previously, which has enhanced clinical practice and better understanding of how to approach bereavement and loss.

Confidence to collaborate with other departments in the hospice as well as increasing the ability to manage a project. The training offered by the QNI in project management, demonstrating value and creative thinking were valuable to my development, not only for the purpose of this project but also my wider role.

Case Study

Mrs R

Mrs R came to the group following referral from her bereavement support worker. She had experienced the loss of her husband under the care of Rowcroft Community Services six months earlier and had received one to one support through Rowcroft Bereavement team.

Mrs. R was tearful on arrival at the first session and she described how difficult it had been for her to come to the group that day and required some initial support. The first session was a gentle introduction with a mindful nature walk. Introductions were made and ground rules established.

After her initial hesitancy, Mrs. R felt able to stay for the first session and subsequently returned to every session. Initially she did not contribute verbally to the group as much as the others but as the weeks progressed, she was able to contribute with honesty and openness, becoming an integral part of the group.

Mrs. R is a creative person and was eager to engage in all activities. In the music group she shared that she was a keen musician but had been unable to play her instruments since the death of her husband. In the session she felt able to pick up and play several instruments and felt this marked a milestone for her. She has since made plans to visit the Bird Hide with a fellow musician to play her harp in the natural environment it offers.

Through joining in with activities, Mrs. R felt her interest and focus was being reawakened. After the pottery session she explained this was an activity she had never done before but intended to actively pursue outside of the group.

Email feedback from Mrs. R

'Thank you so much for today, it was fabulous! Everything you've organised for our sessions has been amazing and has made such a positive impact on my quality of life.'

When the group sessions came to an end Mrs. R felt she wanted to continue some involvement with the hospice so has signed up to volunteer in non-patient roles and also has written a blog highlighting the Nature project, to be published on Rowcroft's social media, part of which is included below.

From blog by Mrs. R

Space in nature

'I was also offered the opportunity to attend Rowcroft's pilot group project, 'Space in nature'. This project offered me a safe, caring environment where I could engage as little or as much as I felt comfortable, without any pressure. Each session had a different activity, all of which were extremely interesting and rewarding and were provided by volunteers who showed great empathy and understanding.'

'We took mindfulness walks in the beautiful grounds, made music, had a tea ceremony, learned about Rowcroft's bees and history, and worked with clay among other things.'

A vital lifeline

'It was such a positive and supportive experience and has helped me take the first steps towards finding a way forward, which I desperately needed. I hope that the project will continue as it offers a vital lifeline to people whose lives have been turned upside down and are in desperate need of support; the gravity of grief cannot be overestimated. I will be forever grateful for the support I have received and I have now signed up as a gardening and 'office saviour' volunteer for Rowcroft as I wish to help support this worthy charity to ensure that others will continue to benefit from its vital services.'

Sustainability and Nutritional Programme for patients in a Community Hospital Setting project

Above: top left: the launch; top right: growing produce; bottom left: Simon Littlefield, George Plumptre from The National Garden Scheme and chef Sarah Agyemang; bottom middle: QNI cake! bottom right: the launch.

Project team

Grahame Hardy, Lead Specialist Nurse in Dementia, Sarah Agyemang, Head Chef, Hawkhurst Community Hospital, Kent

Summary

As one of nine community hospitals in Kent, the aim of the project is to improve and aid the recovery of patients in the rehabilitation facility by introducing home cooked, own grown fruit and vegetables from a garden in the hospital grounds. Patients were involved in harvesting and preparation of produce prior to eating them. The patients really enjoyed being involved and this helped with their rehabilitation. A reminiscence area and sensory garden were developed and well used throughout the summer, and patients and staff said that being outside had a positive effect on how they were feeling and their wellbeing.

The sustainability lead in the organisation was able to utilise the data from the harvested produce to calculate the total harvest and how this had impacted on the carbon footprint of the organisation.

Between March and November 2022, 27 different crops were grown providing a total of 90.94kg of fresh, locally sourced fruit and vegetables to the hospital kitchen.

It was determined that the Hawkhurst Farm produced enough food to offset £386.57 in procuring costs. Herbs such as chives and parsley had the largest impact due to their weight-to-value ratio.

‘Seeing my dream of growing my own fruit and vegetables for patient and staff meals has made me even more passionate about feeding patients nutritious, wholesome food.’

By growing this food on site, this is estimated to have prevented the emissions of 30.54kg of carbon dioxide equivalent (CO_2e). This is approximately the same as a KCHFT fleet vehicle travelling 219 miles.

Patient and Staff Quotes

‘[I] loved the fresh air and the flowers. [I] loved the sun and it felt wonderful on my skin’

‘[I] toured the vegetable garden and picked a strawberry – With permission!’

‘Taking a patient outside is always a high priority when you can. They need fresh air as much as I do. [The patient was] a keen gardener herself so she was happy to go outside and see all the new plants and in particular all the daffodils. The colours are amazing and all sizes, it’s intriguing to see all sizes and colours and lovely to take five minutes out to think of something outside the hospital.’

‘Seeing her outside is wonderful as a healthcare assistant, it’s uplifting to watch and aid her walk around taking it all in, showing me what plants, she has and seeing the signs of spring is a welcoming distraction from being in a hospital all day. I was happy to see her interacting and showing her what we grow and where. Seeing all the spring colours and getting some fresh air is a joy and makes you generally feel so much better, clears all the cobwebs from mine and the patient’s head.’

‘Managing to get outside to get the air and to see someone enjoy what you also enjoy as part of your job really does make you feel enriched in your role. When it gets warmer and longer days, I look forward to taking more people out and hopefully getting my hands dirty’.

Outstanding achievements

The project has attracted a lot of interest, and the Trust was gifted 20 trees from the plant a tree scheme. The chef Sarah Agyemang won the trust health and wellbeing award, as she is a positive ambassador for wellbeing and mental health and promotes and provides nutritional individual choices for choices for patient. She is respected and popular for her tireless dedication, excellence and commitment to her profession.

Several local journalists have been very interested in learning more about the garden, which has resulted in a number of publications and invitations for appearances including articles in KentOnline and Kent Life magazine, alongside an interview of BBC Radio Kent.

The increased promotion of the programme has been beneficial in increasing collaborations with other organisations across the country. These new collaborations have included:

- Head Chef Sarah Agyemang being invited to join Love British Food Hospital and Care Catering Working Group.
- Interest from Nicola Strawther (Chief Dietetic & Catering Technician from NHS England and NHS Improvement).
- Visit from Tim Radcliffe (Net Zero Food Manager at NHS England).
- Simon Littlefield (Director of Nursing and Quality Leadership Team from Surrey Downs Health & Care NHS Trust) visiting the garden with a view to sharing the project design with his trust. Simon has since been successful in an application to involvement with QNI and continues to be in close contact with KCHFT.

Professional Achievements

For Sarah Agyemang our chef the achievements have been multi-faceted and profound. Professionally, the project has provided a valuable channel for upskilling, creating new dishes using fresh ingredients :

'Seeing my dream of growing my own fruit and vegetables for patient and staff meals has made me even more passionate about feeding patients nutritious, wholesome food. It has increased my belief in the power of plant, pick, cook, eat, knowing that patients are getting the freshest ingredients possible.

Creating new dishes with items I've harvested – chocolate courgetti cake, cheese and green onion scones, broad bean and spinach tart, courgette, and carrot muffins is such a joy especially when asking patients to guess what is in them!

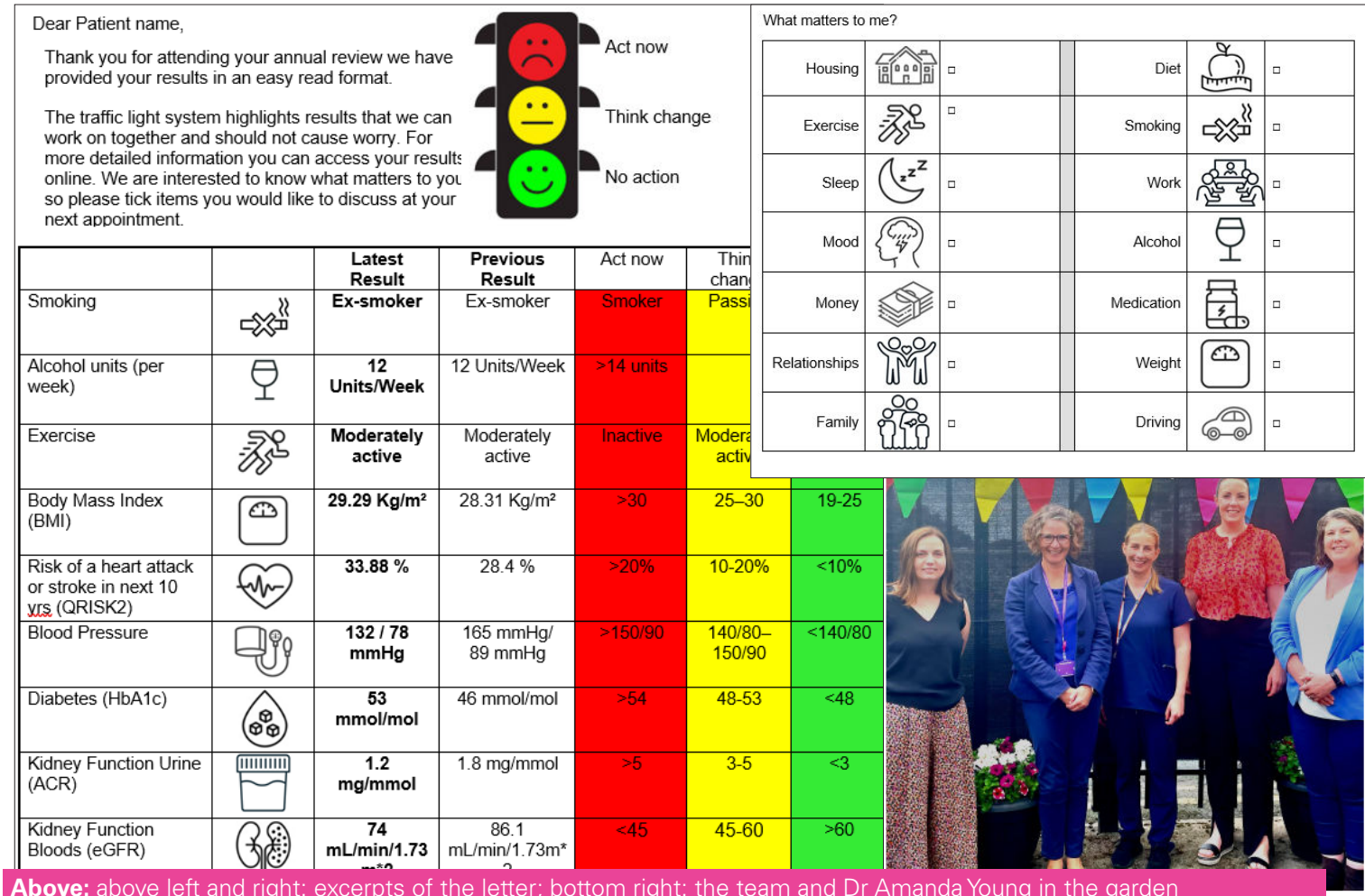
Involving patients in this also adds to the positive power of being outside in nature whilst seeing our produce grow – add to that, patients picking and eating fruit straight from the garden and it brings back so many memories of their earlier years.

As chemicals are never used in our garden, I have been on a journey of learning. Using companion planting to ensure crops are as pest free as possible, crushed eggshells and banana skin fertilizer as feed. Taking these items and many more out of the waste system and using them helps to reduce our waste quantity.

The garden has created a huge positive learning curve for me, and it is something that adds so much to my everyday working life. Knowing patients and staff are enjoying the garden and being involved in the garden brings a whole different meaning to loving my job.'

Sarah Agyemang was also one of three finalists shortlisted for the BBC Morning Live Community Food Champion Award 2023, announced in October.

No Inequalities project



Dear Patient name,

Thank you for attending your annual review we have provided your results in an easy read format.

The traffic light system highlights results that we can work on together and should not cause worry. For more detailed information you can access your results online. We are interested to know what matters to you so please tick items you would like to discuss at your next appointment.

Act now

Think change

No action

What matters to me?

Housing		☐		Diet	☐
Exercise		☐		Smoking	☐
Sleep		☐		Work	☐
Mood		☐		Alcohol	☐
Money		☐		Medication	☐
Relationships		☐		Weight	☐
Family		☐		Driving	☐

		Latest Result	Previous Result	Act now	Thin chan	
Smoking		**Ex-smoker**	Ex-smoker	Smoker	Passi	
Alcohol units (per week)		**12 Units/Week**	12 Units/Week	>14 units		
Exercise		**Moderately active**	Moderately active	Inactive	Modera activ	
Body Mass Index (BMI)		**29.29 Kg/m²**	28.31 Kg/m²	>30	25–30	19-25
Risk of a heart attack or stroke in next 10 yrs (QRISK2)		**33.88 %**	28.4 %	>20%	10-20%	<10%
Blood Pressure		**132 / 78 mmHg**	165 mmHg/ 89 mmHg	>150/90	140/80–150/90	<140/80
Diabetes (HbA1c)		**53 mmol/mol**	46 mmol/mol	>54	48-53	<48
Kidney Function Urine (ACR)		**1.2 mg/mmol**	1.8 mg/mmol	>5	3-5	<3
Kidney Function Bloods (eGFR)		**74 mL/min/1.73**	86.1 mL/min/1.73m*	<45	45-60	>60

Above: above left and right: excerpts of the letter; bottom right: the team and Dr Amanda Young in the garden

Project team

Rebecca Shearer, Lead Practice Nurse, West Road Medical Centre, Charlotte Marshall, Newcastle-upon-Tyne

Summary

West Road Medical Centre is in a deprived area in Newcastle where there is a need to address and challenge inequalities in health such as poorer health outcomes for preventable diseases, like diabetes and cardiovascular disease. There was a need to provide accessible and meaningful information related to annual health checks. Prior to the project, a three-page results letter was sent out to clients giving them blood test results, and included information which was difficult to interpret and make sense of.

The aim of this project was to present results that were meaningful and could be used to address health behaviours to reduce the risk of disease. A letter using a traffic light system was developed: red means act now, amber means time to think about change, and green means no action is required. Patients who wish to know more are encouraged to access their own health records or make a follow up appointment. The letter also focuses on joint personalised care planning and holistic assessment of not just physical health but also mental health and social factors.

This letter was developed by working with community groups and patients. These collaborations have meant that weekly community drop-in sessions provide the opportunity to work with other Newcastle practices to address health inequalities in a different way e.g., vaccination hubs within food banks and local surgeries to increase uptake to prevent disease. The project has now evolved into the wider community to address inequalities with a welfare hub to address the cost-of-living crisis. We are working with the most vulnerable people with representatives from other charities that provide support and advice.

‘The project has given us the opportunity to establish relationships with Year of Care, Connected Voice, Foodbank and Riverside Community Health project. A long-term partnership is envisaged moving forward to tackle health inequalities together.’

As well as meeting the aim of the project, there were unintended outcomes of undertaking this project. Rebecca became a Queen’s Nurse and Charlotte gained a management position within the primary care network due to having increased confidence from being a co-project lead. Inspired by the National Garden Scheme innovation projects that were on the same programme, a disused area at the practice was transformed into an outdoor garden space for staff to utilise.

Outstanding achievements

The project has given us the opportunity to establish relationships with Year of Care, Connected Voice, Foodbank and Riverside Community Health project. A long-term partnership is envisaged moving forward to tackle health inequalities together.

Although Ardens (Ardens Healthcare Informatics, the practice patient record system provider) were unable to develop the technology for the letter, they are utilizing the new version and trying to find a solution.

A video with visuals to explain the year of care process to our patients has been made.

Establishing a garden to support the health and wellbeing of staff allows outside space for staff to gather their thoughts and somewhere to have lunch. We have also included gardening in team building exercises, which was well received by staff.

Professional achievements

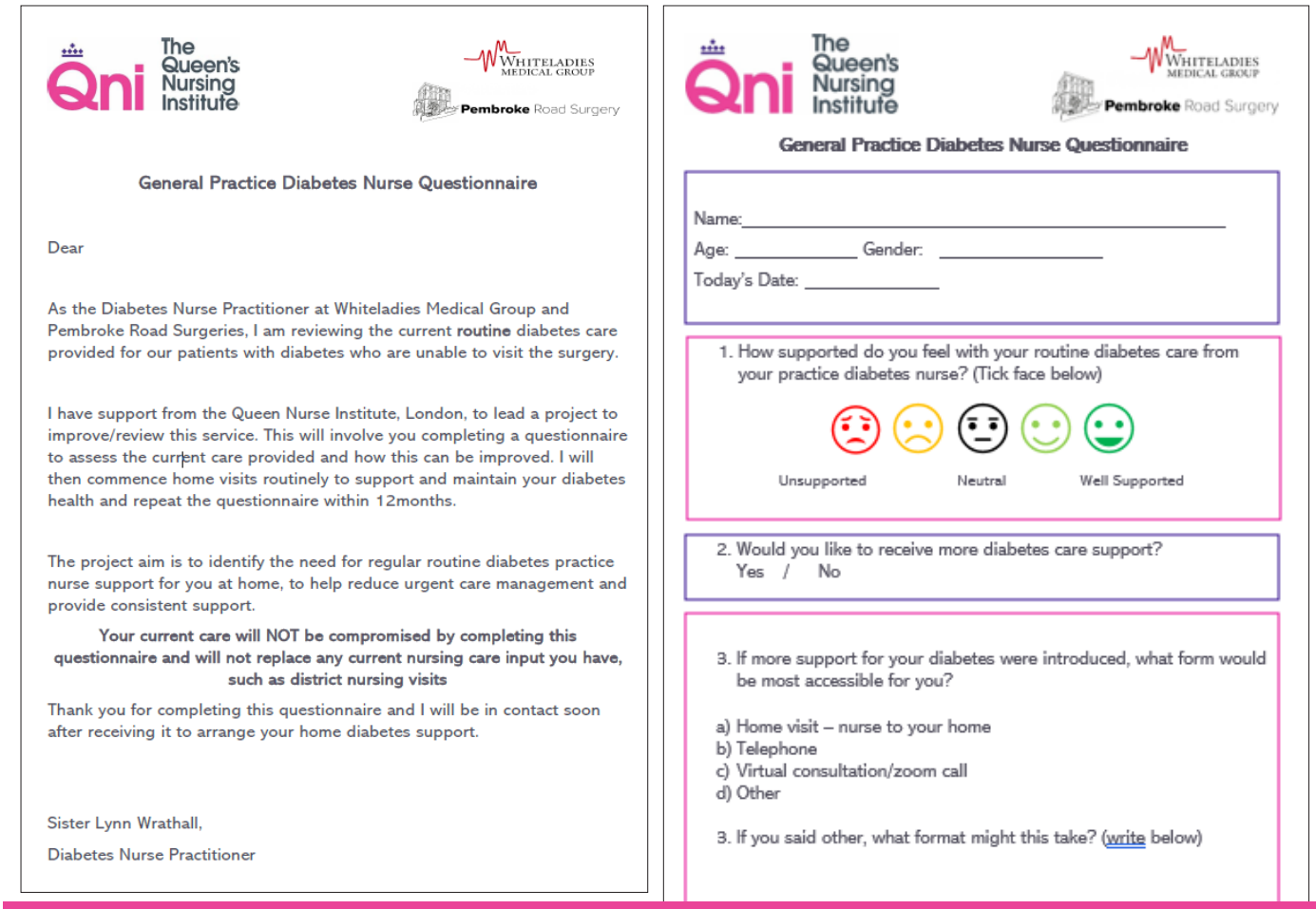
Self-confidence in being a good leader has improved the development of leadership skills, as well as fuelling enthusiasm for nursing. We were thrilled that the project was recognised locally in the Connected Voice Bulletin. As a result of personal development, more compassion and attentiveness is being paid to my team’s needs, with a focus on personal development and retaining the workforce.

The professional links made allowed the development of partnerships, which bridge gaps in expertise and knowledge, developing relationships between primary care and community projects to improve patient care and to understand issues accessing primary care.

Working out of the foodbank one day a week has resulted in collaborative working with Riverside Community Health Project to offer a one stop health shop in other community settings, working to benefit the community.

Although Ardens were not able to create the letter with the technical capacity hoped for, a great sense of pride that the letter was rated so highly that they are considering using it as the template, within their long term conditions package.

Midway Diabetes Support 'Mind the Gap' project



General Practice Diabetes Nurse Questionnaire

Dear

As the Diabetes Nurse Practitioner at Whiteladies Medical Group and Pembroke Road Surgeries, I am reviewing the current **routine** diabetes care provided for our patients with diabetes who are unable to visit the surgery.

I have support from the Queen Nurse Institute, London, to lead a project to improve/review this service. This will involve you completing a questionnaire to assess the current care provided and how this can be improved. I will then commence home visits routinely to support and maintain your diabetes health and repeat the questionnaire within 12months.

The project aim is to identify the need for regular routine diabetes practice nurse support for you at home, to help reduce urgent care management and provide consistent support.

Your current care will NOT be compromised by completing this questionnaire and will not replace any current nursing care input you have, such as district nursing visits

Thank you for completing this questionnaire and I will be in contact soon after receiving it to arrange your home diabetes support.

Sister Lynn Wrathall,

Diabetes Nurse Practitioner

General Practice Diabetes Nurse Questionnaire

Name:_____

Age: _____ Gender: _____

Today's Date: _____

1. How supported do you feel with your routine diabetes care from your practice diabetes nurse? (Tick face below)

Unsupported Neutral Well Supported

2. Would you like to receive more diabetes care support?
Yes / No

3. If more support for your diabetes were introduced, what form would be most accessible for you?

a) Home visit – nurse to your home
b) Telephone
c) Virtual consultation/zoom call
d) Other

3. If you said other, what format might this take? (write below)

Above: left: General Practice Diabetes Nurse Questionnaire; right: Patient questionnaire

Project lead

Lynn Wrathall QN, General Practice Nurse, Bristol

Summary

The aim of the project was to provide general practice nurse support for housebound patients who were self-managing their diabetes but did not require specialist diabetes or district nurse intervention but rather small interventions to continue to self-care. The project lead identified a cohort of patients who would benefit from a practice nurse home visit to enable continuity of diabetes care, thus providing a midway service. Throughout the project data was collected on HbA1C levels, number of hypo or hyperglycaemic events and diabetes related hospital admissions.

In a cohort of 48 patients identified at the beginning of the project, two were admitted to a nursing home and five died of non-diabetes related illnesses. There was a 67% improvement in how supported patients felt, with additional requests for support decreasing from 100% to 6%, and 44% of patients indicating that they had an improved knowledge of diabetes and medication. During the time of the project there was also a 38% reduction in GP visits. Diabetes education has been provided for practice colleagues, reception staff, nursing associates, nurses, and GPs, improving engagement and updates.

The project achieved its aims and also had some unintended outcomes including the Integrated Care Board (ICB) commissioning a specific Diabetes Nurse Practitioner role due to the results of the project. The project lead was successful in being appointed to the role, which will enable other practices to benefit from this model of personalised care.

‘By creating a garden, people have been offered a different way of looking at wellbeing. They have been shown that there are ways to take care of themselves that do not demand anything of them, and that do not cost anything.’

The project lead also became a Queen’s Nurse, as her confidence and professional engagement has increased with a much higher professional profile to support colleagues and make improvements.

A practice CQC visit positively received the project and requested the details and questionnaire for further information. The CQC report read, ‘At the time of inspection, one of the nurses was funded by the Queen’s Nursing Institute to pilot an Innovation in Care Project. They were halfway through the project that was aimed at highlighting inequality of care and planning to improve care for housebound diabetic patients.’

Patient Quotes

- *‘I feel this is gold standard care and I haven’t experienced this before’, [retired Queen’s Nurse]*
- *‘I now feel valued with regular contact.’*
- *‘This gives us security to know we have contact and who to contact in the GP surgery in the future,’*
- *‘Thank you for caring.’*
- *‘What happens when the project stops - do we go back to limited care?’*
- *‘Thank you a million times’.*
- *‘We cannot thank you enough.’*
- *‘Our understanding has significantly improved.’*
- *‘Even our dog enjoys your visits, we feel more engaged.’*

Outstanding achievements

- Developing professional relationships with the patient cohort and their families/carers.
- Identifying clinical need and benefit for routine implementing reviews for the housebound patients by general practice diabetes nurses.
- Improving patient safety.

Professional Achievements

The project lead’s professional profile has been enhanced significantly during the QNI project, gaining more respect from medical colleagues, and co-workers in the broader organisation.

The project duration enabled the identification of care inequality to be acted upon,make a difference, enhance care, provide a voice for patients, motivate others.

Being part of the QNI has boosted confidence in all aspects of work, given a different focus to elements of nursing care, meeting inspirational QNI leaders and colleagues and being allowed time to reflect professionally. The QNI study days were a great way to meet project leads and have tuition from external speakers enhancing professional and personal development – Demonstrating Value being a particularly beneficial day.

Case Study

Background

Annie is an 84-year-old retired district and Queen’s Nurse and social worker from Scotland.

New to our general practice, our first encounter with Annie was at home, as she is housebound due to failing sight. She self-administers four doses of insulin a day, and being a very proud lady would not let her husband administer it. Glucose levels are monitored by a sensor attached to her upper arm, with the readings being large enough for her to read with a magnifying glass. She takes readings over eight times daily via a reader device that she waves over the sensor.

During the home visit inspection, the data identified that the alarms on the sensor were not set, which was rectified. She admitted to routinely night-time waking with low blood sugar, corrected with glucose drinks. By working with Annie and reducing her insulin appropriately, she gained significant reduction in hypoglycaemia within two weeks. Annie’s glucose monitoring has improved with minimal

hypoglycaemic events. She adjusts her insulin doses according to her readings and feels very empowered. She was keen to be referred to a carbohydrate counting course being run locally.

We discussed the benefit of including her husband in the education and skill for administering insulin in case of need and did a teaching session with him. One month later, Annie tripped, breaking both wrists which were placed in plaster casts, and she was unable to administer her insulin for six weeks. Fortunately, her husband's training resulted in continued good glycaemic control.

Annie was diagnosed with diabetes 60 years ago during a post-natal check. She is very proud that she had managed this condition herself, living with her 85-year-old husband. She recalls the Consultant breaking the news – she became emotional and distressed but remembers the consultant saying, 'This is no way to carry on, you have a young family, and you must manage this'. She recalls it being both shocking and hilarious and says it was brutal but factual advice – her husband was at home with the baby. She was admitted for 10 days. She describes the glass insulin bottles, syringes primitive insulin, and only urine sugar monitoring available, which involved boiling the urine in a glass tube. There was little dietary support. She still has her first book 'The Diabetic Life' with its basic guide and diabetes rules, and reflects how management, literature and devices have changed in that time.

Creating a Pain Map of Cornwall project

Above: top left: the pain cafe advertised; top right: Dr Jim Huddy; bottom left and right: the website: pain.cafe

Project team

Deborah O'Nyons, Professional Lead For Personalised Care and Health Coaching Clinical Lead; Dr Jim Huddy, General Practitioner, Cornwall

Summary

Management of chronic long term pain in Cornwall is disjointed and treatment options are often medicalised when there are alternative approaches that can have a positive impact on living with chronic pain. This project aims to train one or two 'pain champions' from each of Cornwall's primary care networks using the 10 footsteps for 'living well with pain', adopted from France's Cole's model as the first phase of a five year project to improve pain management in Cornwall.

50 trainees were recruited and trained and the Chronic Pain in Cornwall website was published for people with chronic pain. The website includes education, links, signposting and information to support self-management and signposting to the right services, medical or non-medical https://pain.cafe/. This has been well received and the online sessions have been positively evaluated.

A conference at the end of year one was held at the Eden Project where trainees, people with lived experience of chronic pain, the chronic pain in Cornwall team, ICB representatives, and some national experts got together to consolidate what had been achieved and where the project was going next.

The aim of the project was achieved with some unintended outcomes, including more health coaching training, establishing a community of practice to share best practice, and to co-create and develop strategies, resources, tools, and techniques to manage pain.

‘I find that people come to our group with a positive attitude but if you’re having a bad day that’s alright too as there are people there to support you and give you that much needed hug (physical or verbal) and to tell you that tomorrow will be a better day.’

Expert patients have been central to the training and attending the pain cafes being developed. We have also done joint working with Southwest Academic Health Science Network to enable local development, consider funding opportunities, and to support regional initiatives.

Outstanding achievements

- The project was awarded an award for personalised care from the NHS SWIPC Personalised Care Awards.
- Professor Alf Collins, Clinical Director of Personalised Care NHSE tweeted about the project and hailed it as good practice.
- We also made the BBC news and were interviewed by local radio stations (https://www.bbc.com/news/uk-england-cornwall-64451040).
- Pain cafes have been established in Perranporth, Truro and Pan Cornwall – currently reaching about 10 people in each café – this is growing and we have a number of online contacts as well.
- Pain Café Learning and Launch at the Eden project (27th January 2023) was attended by 70 people from across Cornwall, representing a wide range of health professionals and community sector roles.
- There are a number of cafes in preparation for launch in Wadebridge, Newquay, Falmouth, Liskeard, East Cornwall. Most are in partnership with other agencies including GP surgeries, Age UK, Echo Centre, social prescribing groups and local activity e.g. yoga and arts provision
- Menopause groups in St Agnes (now with 40 people) and Truro (about to launch) are offering specific support regarding pain and other symptoms.
- 10 Footsteps to pain: implementation and rollout of training and resources to chronic pain users.
- Created a mantra of ‘skills not pills’
- Armchair yoga, craft and walking groups established in Perranporth.
- Personal stories of not attending as many GP sessions and increased self-management.
- Pain cafés have been established in Perranporth, Truro, Bodmin, Helston and St Austell with some cafes having over 20 attendees.
- ‘Living through pain’ conferences were delivered in Bedruthan Steps Hotel and Truro and Penwith College.

Professional Achievement

People with chronic pain are an under-reached group with significant unmet health and emotional needs and all work undertaken in this phase of the project has been worthwhile.

The development of a cross sector team working virtually and innovatively to deliver something new, and person centred with a shared vision and passion to enable people to be put back in the driving seat when it comes to managing their pain.

Case Study

Polymyalgia Rheumatica (PMR) & Me

Before October 2019 I'd never heard of PMR. During August and September, I had experienced some pain and stiffness, mainly in my leg muscles, but nothing that Voltarol gel and painkillers didn't ease then suddenly over the course of a weekend PMR hit me. I was 64 but thought I had been turned into an octogenarian overnight. The pain was indescribable and with it came an overwhelming weakness in all my main muscle groups. I've heard it said that PMR stands for 'Pretty Miserable Reality', and I think that's pretty apt. Over time it can affect not only your physical health but also your mental health and your ability to enjoy life in general.

There are no outward signs of what's going inside your body, the pain that's ravaging every corner of it; a pain that doesn't let you sleep, makes everyday tasks such a showering, hair washing and using a hair dryer nigh on impossible at times, but you look okay to everyone around you. Going for a walk with friends or family becomes a huge if not impossible task – something you wouldn't have given a second thought to before.

So how can you possibly explain to family and friends this new world that you have now entered? Quite simply you can't, partly because you're struggling to comprehend it yourself. It's not pity or sympathy that you need it's help and support. You also need ideas for coping mechanisms and that's where the Pain Clinics play a very valuable role. Pain is pain, no matter what part of your body it comes from, your age or your gender. What I'm finding useful about the Pain Clinic is exploring with other people how they live with and manage their pain. We all have pain for a multitude of different reasons and when we get together the reason is rarely discussed, it's almost incidental. Our common ground is simply pain and the best practical solutions (not involving medication) for distracting ourselves from it. I've found the group document – Ten Footsteps Your Journey to Living Well with Pain very useful. It's a reference document of the core principles of managing pain.

I find that people come to our group with a positive attitude but if you're having a bad day that's alright too as there are people there to support you and give you that much needed hug (physical or verbal) and to tell you that tomorrow will be a better day. We understand each other and what it's like to live with persistent pain that rarely takes a day off! How we wish it would – wouldn't it be wonderful to just wake up one morning and find that pain was gone for the day, but realistically we know that's unlikely. So we try chair yoga; mindfulness; sharing ideas on activities we enjoy; books we've read; walks and days out we've enjoyed for those fit and well enough to enjoy those activities. Our focus is on what we can do and not on what we can't. We have a WhatsApp group which we use to keep in touch in between meetings – just friendly messages to check in on each other. There's no pressure, everyone can choose to dip in or out, but if you need anyone you know there's someone there.

The Pain Café to me is about being positive, offering mutual support, inclusivity for all and knowing that you're not alone with your pain. Surprisingly enough there are many more people living with chronic pain, more than you would think and I believe that we can all support one another in a positive way.

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