



PULBOROUGH PATIENT LINK AND YOUR MEDICAL GROUP WORKING TOGETHER TO GIVE YOU THE BEST POSSIBLE CARE

NEWSLETTER NUMBER 30 SUMMER '15

This issue includes articles on:

The Care Act

Prescription Ordering

Bereavement Support Group

PMG Update

A Review of Public Involvement in the Health Service

Pacesetter Award



A date for your diary -

The next of our regular Public Meetings in Pulborough Village Hall is on Monday 13 July

when

Dr Tim Cantopher

BSc Immunology MBBS FRCPysch Consultant The Priory Hospital Woking will give a talk entitled

DEPRESSIVE ILLNESS: THE CURSE OF THE STRONG

His field of interest is adult psychiatry, with particular emphasis on stress-related illness, depression and addictions

Talk 6.30pm

CHAIRMAN'S LETTER

So the outcome of the Election is known, but it is unlikely to create a health service that <u>all</u> of us will think is perfect. Certainly all of the promises that were made are unlikely to be fulfilled. Therefore, the task of the Pulborough Patient Link will be to continue to serve as a powerful pressure group for patients of the Pulborough Medical Group.

Our meeting at the AGM gave us an opportunity to hear the views of the top players in health on the way ahead, and to make them aware of our issues and concerns. And we must start to be more vocal in raising our issues.

I often reflect on my experiences in work. Like me, many of you will recall 'business process re-engineering' and 'Total Quality Management'. The intention was to satisfy the customer and to make the underlying processes more efficient (and less expensive). To put it simply, any process that was considered unsatisfactory was examined by those involved, measurement was made of the steps in the process and improvements were then made. Commitments to deliver were sacrosanct.

Of course, in health the primary customers should be us, the patients, but we are expected to be (and seem to be) grateful for whatever we are given, and merely complain with friends over a cup of tea - and the friends often have similar poor experiences. Last year I had to wait, on discharge, over five hours for one medicine to be given to me from pharmacy. Several patients were in the same situation, and friends and relatives who had come to take us home had the same wait. Why?

One of the key roles of PPL is to raise these issues and help identify solutions. Although Pulborough Medical Group serves us well, there are issues and challenges in the Pulborough district with community services and this Newsletter devotes much space to keeping abreast of developments in this area both locally and county-wide.

Mental health is being increasingly identified as a priority for attention and action. Therefore, our next Public Meeting on July 13th will be on this subject and, in particular, depression. I hope you will encourage friends and family of all ages to attend. I was shocked to learn that the biggest cause of death among males under 50 is suicide!

Please let us know your concerns and your satisfactions by phoning me on 01798 875051 or emailing to info@pulboroughpatientlink.org or speaking with any member of the Committee.

Enjoy the summer.

David McGill



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CARE AND SUPPORT IS CHANGING

In April 2015 the Care Act brought about the biggest reform in social care for 60 years.

It introduced new duties and responsibilities for local authorities about care and support for adults. 'Care and support' is the term used to describe the help some adults need to live as well as possible with any illness or disability they may have. It includes the help given by family and friends, as well as any provided by the County Council or other organisations.

The Act makes care and support more consistent across the country, and puts people more in control of the decisions surrounding their care. It will ensure that not only are people supported to keep as well as possible, but also that they can get the services they need to help prevent - or delay - their care needs from becoming more serious.

What has changed?

People with care and support needs, and carers, will be able to access advice and information regardless of whether they pay for their own care or receive funded support from West Sussex County Council.

The County Council must offer an assessment to anyone who appears to need care and support, regardless of their financial position or whether their needs are likely to be eligible. This means that if a person feels that he/she, a friend or family member needs to have their care and support needs assessed, the County Council will do so.

Other major changes introduced by the Care Act include:

• Deferred payments - these agreements will enable people to meet their care costs without having to sell their home during their lifetime.

- Support for carers for the first time carers are entitled to support in their own right. They may be eligible for a personal budget to pay for things which help them to care, such as a short break.
- National minimum eligibility criteria this means people will get the same access to support wherever they live. In West Sussex, all currently eligible for care will continue to be eligible.

In April 2016 further changes will be introduced under the Care Act with the final detail available in October 2015. The main highlights include:

• Lifetime cap on care costs

Adults will see the cost of care capped at £72,000 (excluding living costs). Individuals will need to set up a care account to keep track of their spending, and these accounts will take effect in April. The care cap will not be back-dated, so money spent on care before April 2016 will not count towards the £72,000 cap.

Anyone who develops care needs before the age of 25 will get free care for the rest of their life.

Residential means-test threshold

The threshold will rise from £23,250 to £118,000 where property is taken into account, or £27,000 without property, meaning that anyone with savings or assets worth less than that will get help with the cost of their residential care.

What do you need to do?

If you already receive care and support from West Sussex County Council you don't need to do anything. The County Council aims to review the care and support that people receive on a yearly basis, so the new legislation will be taken into account at the next planned review. This may result in some changes to customer's care and support, but the Act is designed to benefit people with care and support needs. It may be that people who weren't eligible before are now eligible, and others may be eligible for more care and support.

If you are thinking about care and support for yourself or a loved one, make sure you get good information and advice to help you make the right decisions.

You can find everything you need to know on our website **www.westsussexconnecttosupport.org**. Alternatively call our **CarePoint on 01243 642121**, where a specialist team is on hand to offer information and advice.

If you already pay for and arrange your own care and support you don't need to do anything now. How people pay for their care isn't changing until April 2016, but it's never too soon to get good information and advice on planning and paying for care.

WSCC's **Carewise** care funding scheme can help, simply visit <u>www.westsussexconnecttosupport.org/carewise</u> or call **CarePoint on 01243 642121.** They can discuss the options available to you and offer trusted advice through a team of local specialists, based on your individual circumstances, to help you with long-term planning.

If you are a carer – someone who looks after an adult family member or friend – you should make sure you know where to go for good information and advice to support you in your caring role. Either call West Sussex County Council's **CarePoint** or contact **Carers Support West Sussex** on **0300 028 8888** or visit <u>www.carerssupport.org.uk</u>

If you think that you may be affected by any of the other changes introduced by the Care Act please visit **West Sussex County Council at <u>www.westsussex.gov.uk/careact</u> or phone 01243 642121 to find out more.** *West Sussex County Council*



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PRESCRIPTION ORDERING AND SYSTMONLINE

In accordance with national guidelines and in line with all other surgeries locally, our ability to order repeat prescriptions by telephone is being discontinued at the Pulborough surgery. So how are those of us who use the telephone service going to order prescriptions in the future?

For those not able to use the online system, then the paper method is to use the drugs list that we always receive with our medicines when we collect a prescription. The items required should be ticked and the completed list left at the surgery or chemist by you, a family member or friend. The list can also be posted to the surgery.

Of course, we all know the need to allow sufficient time – at least three days and, to be sure, a week - for the prescription to be written and medicines, which may need to be ordered, dispensed.

Repeat prescriptions can also be ordered online. PMG have recently introduced a system called SystmOnline and this is convenient and relatively easy to use. This is PMG's preferred method for online ordering as it is received directly by the Practice and you are encouraged to change to this method if you have not already done so. For security reasons, before you can use this service you need to register at the surgery. You are asked to take some proof of identity. The whole process takes no more than two minutes and you will be given your own personal login details. Then you are ready to order in this way. For those who are computer-shy, then perhaps a carer, friend or family member will be able to help – or the paper option will always be available.

SystmOnline also allows us to book appointments with doctors – but not yet regrettably with nurses. This is useful for routine appointments. However, appointments can still be arranged by phone and this is the best way of securing urgent medical care.

If you have any issues about these changes, please let the PPL know. David McGill

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Don't feel isolated, lonely or alone BEREAVEMENT SUPPORT GROUP

Some time ago I wrote a piece for the PPL about the Bereavement Support Group, explaining its background and what we do and where we do it. Since then, sadly, more people will have found themselves in the situation where they have lost a loved one. Our group is totally free, independent from the doctors and it is run voluntarily by me and Mary-Anne who was a district nurse in our area until her recent retirement. I also worked in the NHS at the Royal Marsden Hospital until I retired. So our backgrounds are in the caring profession.

I will repeat some of my earlier information for new readers. Often when people are bereaved they are offered counselling, but many do not want to talk to a stranger. Our Support Group is a self-help group – people come along and find a small friendly group of people who are all bereaved so know how new members are feeling. It is a place where you can feel safe and do not have to explain anything. WE DO NOT TALK ABOUT BEREAVEMENT. This may sound strange, but when you think about this statement it makes sense. We all know why the group meets and that everyone has lost a loved one. We do not need to talk about it; in fact, it is a relief to talk about something else and just relax with friends for a little while. Of course, if anyone wants to talk about anything privately on a one-to-one basis they are free to do so. Mary-Anne and I are always there to listen and help if we can.

Meetings are held once a month on the 2nd Tuesday at 2pm. Sometimes we have a speaker to give us a short talk about anything which may be of interest. Sometimes we just sit around and have a cup of tea and a piece of cake and just have a good chat. It is not a sad group. In fact, it is very cheerful. We do not have a meeting in June or December as we then go out – for afternoon tea and for a Christmas lunch. I also organise coach outings with Roadmark Travel and we go to some lovely and interesting places. This is something which you probably wouldn't do by yourself but, with a small group, it is possible to go out and enjoy yourself.

At the moment our group is very small as some people move on once they feel better and more confident in themselves. However, some people have been coming for many years and continue because of the friends they have made.

In the immediate days after the loss of a loved one usually you are in a state of shock, sadness and total loss. Also there is so much to do with making all of the arrangements that you are kept busy. Once this time has passed, that is when the loneliness and isolation creep in. That's when it is useful to have a group like ours to turn to. We don't make judgements, interfere or impose our ideas. We are just there to give support when needed.

Anyone who has been bereaved is very welcome. It doesn't matter when this happened – recently or years ago. Neither does it matter what the loss is – a family member, friend, divorce (loss of a marriage) or a pet. <u>A loss is a loss.</u> Any loss is a bereavement and can have the same devastating effect.

If you think you would like to join our group either come along at 2pm on the 2nd Tuesday of the month (not June or December) to the ground floor of the Pulborough Medical Centre. You do not have to be registered with the Pulborough Practice – everyone is welcome. Alternatively, please ring either myself or Mary-Anne on the numbers given below.

The first step is the most difficult, but there is a warm welcome waiting for you. Come and make new friends – don't feel alone.

Sue Jahan – Joint Group Leader Telephone: Sue 01798 813330 Mary-Anne 01798 813306

OSTEOPOROSIS

Osteoporosis, as all who came to hear Dr Sanjeev Menon's excellent presentation in March will remember, is 'a systemic skeletal disease characterized by low bone mass (a change in bone physiology) and a deterioration of bone quality, with an increase in bone fragility and susceptibility to fracture', and this change is clearly shown in these pictures of 'normal' bone and osteoporosis.

Dr Menon, who is a Consultant Rheumatologist, explained that the text book definition of osteoporosis is 'a disease which decreases bone strength and therefore increases the risk of



(normal) bone is comprised of thick, interlinking trabeculae

fracture'. As you can see from the picture on the left, healthy



('*little beams' – in this context, a general term for supporting or anchoring strands of connective tissue*), while the osteoporotic bone is thin and some of the connections are broken. He said that the disease is no longer considered as just a low bone mineral density (BMD) problem. There are multiple factors affecting the strength of bone and therefore fracture risk – including BMD and bone architecture. He said it is not only the strength of bone that is important, but the flexibility of it also.

This can be related to a steel bridge. A high quality bridge is not one with just a lot of steel. Both the steel and the way in which it is structured combine to make the bridge strong. The same can be said about BMD and bone architecture, with BMD being a good indicator for increased risk factor.



This chart shows the incidence of fractures in women at specific parts of the body related to their age, with the red showing wrist fractures caused where the hand is outstretched when falling, fractures in the vertebrae are

shown in yellow, with the mauve showing hip fractures. As can be seen, over 50 years of age, hip and vertebral fractures increase as we get older, while wrist fractures remain fairly constant. 1 out of 2 women over the age of 50 will experience an osteoporotic fracture during her lifetime.

Dr Menon stressed the importance of diagnosing osteoporosis as fractures are common and will increase with the ageing population. After a vertebral fracture, 1 in 5 women will suffer another within a year. This type of fracture quickly leads to further vertebral fractures and increases the risk for hip fractures over 3-4 years.

Assessment of a patient's osteoporosis can be achieved by: History and evaluation Laboratory evaluations – blood tests Radiographs, DEXA scan, isotope bone scan or MRI scan

With spinal osteoporosis there are no early warning symptoms. Indications may include:

Acute, acute on chronic, chronic back pain Height loss Spinal curvature Prominent belly with an upper crease, bloating and nausea Restricted lungs – more breathless The risk factors for hip fractures are: Bone Mineral Density (shown on a Dexa scan) Age and sex (both of which have already been mentioned)

However, independent of these are: Parental history of hip fracture (may not be relevant if parent very elderly when the fracture occurred) System corticosteroids If you have rheumatoid arthritis If your daily intake of alcohol exceeds 2 units If you have a prior fracture when aged over 50 If you are currently a smoker If your BMI (body mass index) is less than 20

Dr Menon went on to explain the clinical aims in treating osteoporosis, which are:

To identify patients at increased risk of fracture To reduce the incidence of fractures

To aid understanding of the disease, treatments and the choice of therapy

Treatments include:

Lifestyle advice regarding quantity of alcohol consumed, the effects of smoking and the benefits of exercise Drug treatments

The various pharmacological therapies available include:

Calcium and vitamin D

Bisphosphonates – Alendronate, Risedronate, oral or intravenous Ibandronate, intra-venous Zoledronate. Dr Menon said, when taking Alendronates, how important it is to follow the advice given of sitting or standing – not lying down - and having nothing other than water for 'at least half an hour' (not even tea or coffee) to give the tablet time to work properly.

SERMs – Raloxifene (SERMs are selective estrogen receptor modulators, developed for postmenopausal women to reap the

benefits of estrogen, while avoiding the hormone's potential sideeffects.)

Hormone Replacement Therapy

Teriparatide (Forsteo) – self-administered injections daily for 18-24 months

Strontium (Protelos) - this drug is prescribed for patients who cannot use other medication. However, it is not suitable for those with ischaemic heart disease, cerebrovascular disease, uncontrolled hypertension or peripheral vascular disease

'Hot topics' in Osteoporosis are: *Atypical fractures (ie unusual fractures) Drug holidays FRAX*

Atypical fractures of the femur rise with duration of treatment from 5 cases per 100,000 patient years to 1 case per 1,000 patient years after 10+ years of treatment. However, evidence suggests the well-known benefits far outweigh the relatively low risk of these rare, atypical fractures. For every 10,000 high-risk patients undergoing bisphosphonate treatment, approximately 100 hip fractures and 750 fractures at other sites are prevented, whereas only 3 to 6 atypical fractures could be expected.

Also mentioned was the possibility of 'drug holidays'! Alendronic acid taken for 5 years and then stopped results in an increase in vertebral fractures, while continuing for a further 5 years gives vertebral fracture protection. At 5 years, risk should be assessed to determine whether drugs be continued or suspended. If the T score as shown in the diagram overleaf is < -2.5 or there have been hip/vertebral fractures or steroids then alendronic acid should be continued. If, however, the risk is moderate/low eg > -2.5 (osteopenia) and there have not been any fractures, then a 2 year 'holiday' is suggested.



Dr Menon also mentioned that 1 ADCAL per day should be sufficient – but stressed that any suggested changes to your current medication should be talked through with your doctor.

His final suggestion was that, if you are interested in answering an on-line questionnaire, it will calculate your risk of osteoporosis. This has been produced by a professor at Sheffield University and can be found if you google the word FRAX.



PMG UPDATE

Following the appointment of Dr Nikki Tooley as a Partner at Pulborough, we were delighted to welcome Dr Eloise Scahill to our clinical team as a salaried GP. Eloise works at Pulborough 3 days a week, but also spends Tuesdays working in A&E at St Richards Hospital. Dr Carole Campbell has also now come back after her maternity leave. Our two GP Registrars - Dr Luke Webb and Dr Charlotte Mance - are still with us; Luke remains in post until end of October 2015 and Charlotte until beginning of August 2016. In August 2015, we will be joined by Dr Rosanna De Cato as a full-time GP Registrar until the end of July 2016.

Amongst the support staff we have had a few changes in our reception and, following recruitment, we have several new members of staff joining our team – to replace staff who have left, but also additional staff to help support the workload in our call centre, reception and prescriptions.

In April we reintroduced our Travel Clinic – details and the online travel risk assessment form are available on our website – <u>www.pmgdoctors.co.uk</u> Please click on the Clinic/Services option strapline underneath the telephone numbers. If you require this service, it is sensible to make provision well in advance of your expected date of travel for relevant travel vaccinations.

PMG's travel clinic can provide your free NHS Vaccines. These include; Diphtheria, Tetanus, Polio, Hepatitis A, Typhoid and Cholera. We can also provide the following private vaccines; Meningitis ACWY, Menveo Meningitis, Rabies (3 injections required) Hepatitis B, Japanese Encephalitis.

If you are due to travel and require some travel vaccinations, it is very important that you fully complete the <u>online travel risk</u> <u>assessment form</u> and return this to the surgery at least 8 weeks

prior to your expected date of travel. This form will be reviewed and one of our nursing team will contact you to discuss your requirements and book you the relevant appointment for your vaccinations. Please be aware that some travel vaccines are ordered on a private prescription and these incur a charge over and above the normal prescription charge. This is because not all travel vaccinations are included in the services provided by the NHS.

Alternatively, the risk assessment form can be collected from our reception desk on the first floor of the Practice. For more information, please review our General Travel Advice Leaflet and Pre Travel Letter on the website.

We have made a couple of changes to our reception area on the first floor :--

The self check-in screen is now sited by the main entrance door to the first floor – this gives more space by the reception desk and allows more privacy for patients using the self-check in screen. If you are simply coming to the Surgery for a routine booked appointment, please do use the self check-in screen; this will free up our reception staff to deal with other queries.

To assist reception staff and provide more privacy for patients talking to the receptionist, we have set up a 'queuing system' in the reception waiting area and would be most grateful if patients who need to speak to a receptionist, would queue behind the belt system and wait until they are called by the receptionist. Whilst the previous patient may have moved away from the reception desk, the receptionist may still be entering information onto the computer or processing the query from that patient; once they are free to give the next patient their complete attention, they will call the patient.

PUBLIC HEALTH AND PUBLIC INVOLVEMENT IN THE HEALTH SERVICE

Should patients and the public have a say in running the National Health Service? It would be interesting to have a referendum with compulsory voting with the two options: "yes" or "no" and perhaps a third option of "don't know". I think that it is far from clear what the result would be. If a majority answered yes, how could people realistically be given this kind of power? How much power do patients and the public have at present? If we had more power would things improve?

Politicians say we should all play a part in running the health service, and successive governments have tried many different ways of involving people. David McGill asked me to write about changes I have seen during my 16 years as chairman of Pulborough & District Community Care Association - and here is a taste of them.

Stuart Henderson and I were volunteer members of Worthing Community Health Council (CHC) for some time before CHCs were abolished in 2003. Since 1974 the 204 CHCs across England and Wales acted as the people's advocate and the patient's friend. We had the power to inspect services (apart from General Practice), and to veto proposals for substantial changes to health services, including hospital closures. CHCs were unusual organisations as they were statutory bodies, but were run by local people with a substantial number of volunteers nominated by local councils and voluntary groups. Thev campaigned for patients' rights and had a small staff in each area, housed in offices where people could visit to discuss, in confidence, their complaints about health services. Stuart told me about his regular monitoring of Worthing A&E department and also related how interesting he found Facilities Management at Worthing. This department was responsible for the diverse and large area of what could perhaps be best described as hotel services of the hospital, from the availability of bedding to that of syringes and wheelchairs. I paid visits to the mental health ward then located at Swandean and to the older persons' wards at Southlands. We spoke to both patients and staff and freely entered anywhere in the hospital. It was possible to find out a great deal about how patients and staff felt and how the system was running. We wrote reports about our visits which were discussed at CHC meetings of staff and volunteer members, and action taken as necessary. Independent as they were, CHCs were sometimes seen as mouthpieces for the local health services and certainly meaningful outcomes varied greatly between different CHCs.

In 2003, instead of the 204 CHCs the Commission for Patient and Public Involvement in Health was set up, working via 571 Patient Forums; and Local Patient Advocacy and Liaison Services (PALS) were established to investigate patient complaints. By this time Parliament had required the NHS to involve patients and the public in the development of services, and local authorities had to set up Overview and Scrutiny Committees with the right to monitor local health services. These local authority committees should bring more democracy to the NHS and, in 2012, scrutiny of social services also became the responsibility of local Overview and Scrutiny Committees. The public can attend the meetings of this committee in West Sussex, can ask questions and may be asked to give information in certain cases. When items of significant public interest are being discussed, the scrutiny committee's proceedings are webcast live and are archived after the meetings, so we can all be fully informed and have a say in this work.

In 2008 politicians, determined on continuous change, replaced the above mentioned Forums with Local Involvement Networks (LINks). Stuart Henderson was a member of both our local Forum and then of our local LINk. Indeed, it was the LINk idea that gave the name to our patient participation group -Pulborough Patient Link - and this group is a place where real dialogue can take place between public, patients and those who provide our local health services.

The national LINk organisations have now been replaced by 152 Healthwatch organisations. This does not in any way affect our patient participation group in Pulborough which is not part of the national organisation. Healthwatch was intended to be the public's and patients' champion for health and social care; and to be an independent organisation, able to employ staff and involve volunteers. In practice, each local Healthwatch is funded by the local authority out of money provided by the Department of Health. Healthwatch is charged with championing people's social care, but this is provided by the authority that pays Healthwatch. The situation is not ideal, and from the start the Chairman of Healthwatch England reported that their funding was only 3/4 of what had been promised. Their remit is huge, and includes Adult and Social Services, the NHS, Care Homes and Nursing Homes. In our area, Healthwatch is responsible for both East and West Sussex and I seriously doubt that it is possible for them to do this job effectively.

There was a slow, steady evolution in ideas about patient's rights in the days of CHCs, but since 2003 there has been a sea change *in policy terms* in the NHS's commitment to public involvement in the service. For policies to become effective in practice, however, I believe changes are still needed and I hope that very soon, realistic allocation of responsibilities and funding will make public and patient power a genuine force in the NHS.

Gwen Parr



pulborough patient link

- your voice in local health





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PMG APPLICATION FOR PACESETTER AWARD

If the UK health system performed as well as that of Sweden, as many as 1500 children might not die each year

75% of children seen in A&E are fit enough to be discharged home

Over 1/3 of short stay admissions in infants are for minor illnesses that could have been managed in the community

A 5 year old child will see a GP 6 times per year

Children, young people and their carers are high users of the NHS and it is important that they receive high quality care in the right place. Hopefully the above facts will have helped to illustrate the context in which this award is founded, and why PMG have decided it is an important award to achieve in order to improve the healthcare for children and young people in our community.

The **PACESETTER Award UK** aims to encourage the whole provider team to commit to high standards of integrated, coordinated and accessible care that are designed around the needs of their local population. By achieving the award, it will serve as a kite mark or stamp of approval regarding the provision of high quality care PMG aim to provide for our children and young people. Patients and their families form a key part of the whole Award system. The four Elements are: **P**atient and Carer Engagement, **A**ccessing Services, **C**linical Pathways Implementation and **E**ducation of both staff and also of families, and I will illustrate each area further now.

Patient and Carer Engagement – The first aim is to understand the challenges within the PMG community that our children, young people and their carers face when it comes to their health.

By utilising e-mail and phone-led questionnaires and speaking with carers in family centres we hope to achieve this goal. If you would like to contribute to this project please contact the surgery for more information.

Accessing Services – The next part is to look at the processes in place that encourage or dissuade our community from accessing the right medical care and advice in the right place. Studying the challenges regarding the current appointments system with specific regard to children and young people will allow us to assess an appropriate and safe system for access.

Clinical Pathways Implementation – This will include an audit of our safeguarding policies that are in place to identify, protect and support vulnerable families appropriately.

Education – Following on from the areas identified in engagement activities we shall look at ways of improving knowledge on managing children and young people both for children, young people and their carers, as well as for those clinicians and support staff involved in their healthcare.

By striving to improve the way people access healthcare, and by studying the processes in place to ensure appropriate and high quality care in a way that is based on the areas identified by the carers and young people using the services, PMG shall aim to achieve the PACESETTER award.

As you can see, patient and carer feedback will be at the core of helping us to evaluate and improve our services to children, young people and their carers, and I look forward to the discussion, support, implementation and feedback from our community as I lead this project in the next year.

Nikki Tooley - GP Partner



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