Keeping Well?

The Newsletter of the Nuffield Patient Group

Autumn 2014 Issue 6

Welcome to your bumper Keeping Well?

The Nuffield Patient Participation Group does its very best to represent your views. We will be running a survey in November. We are always keen to recruit new members, and we are particularly keen to hear from younger patients in the practice who could spare just one hour every quarter to help the Practice to understand your needs better.

The next meeting of the Group will be held at the Practice on Tuesday 14 October at 6.30 p.m. We'd love you to join us; if you can come, please let us know by e-mailing Catherine Simonini (catherine.simonini@nhs.net).

In this issue of *Keeping Well?*, we bring you news not only from the Nuffield Practice but also from the county and, indeed, the whole of NHS England! As usual, we also have a patient story, from Robert Owen (page 4), and our regular feature from Sarah Chapman (page 6).

Care.data: a personal view

by Graham Shelton

Remember all the fuss about the government's plan to collect and use data from our general practice medical records? Not just for our personal care but for wider insights into the health of the nation?

The government has been collecting and using anonymized hospital records in England since the 1980s without asking anyone, as far as I know. Now we are being asked about our GP records, and the problem is that many feel that the privacy of their personal data may not be safe in public hands.

As a result of public disquiet, NHS England agreed to undertake further public consultation. One part of that consultation, which is still in progress, is a series of public events. In September this year I went to one in Oxford, at which I hoped to hear all the arguments and decide for myself what I should do about my own data.

Disappointingly, the meeting didn't provide all the pros and cons, but I write here what I concluded after a bit of digging.

This is a personal opinion rather than the view of the Nuffield Partners.

Why patient data from general practice?

As a scientist involved in the medical field, I know from experience that collecting huge amounts of data is truly

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useful in giving accurate insights into the real world. Having data from general practice as well as hospitals would significantly enhance our ability to take a complete, balanced view of health care and disease management strategies, in particular:

• patterns of disease locally and nationally

• which treatments, and which methods of treatment delivery, work best

• who is at risk and who needs targeting for prevention

• how best to use limited health and social care resources to provide the maximum possible benefit to the most people

• the quality and value for money of our health, public health and social care services in different places.

What is the plan?

The plan is to store the information securely at the Health and Social Care Information Centre (HSCIC), which was set up last year as the central source of health and social care information in England. This has strict, legally binding, confidentiality rules about access and appropriate use to improve patient care. There would be three levels of data access:

• anonymized (for public reports by HSCIC)

• potentially identifiable (but excluding date of birth and postcode)

• identifiable (requiring explicit patient consent).

Other countries, such as Sweden, already keep much more complete records about every aspect of every resident from cradle to grave, and, as far as I know, nothing really bad has happened.

The problems

• These data will not be used directly to assist your own health care, so the hospital that admits you while you are on holiday will not be able to check your medical records for things like allergies and other problems.

• While your name will be removed from your records before they are stored centrally, your date of birth, NHS number, gender and postcode will not. With the Internet, it could be easy (if illegal) for someone to connect your name to your records if they choose to do so.

• The information will be available to organizations outside the NHS 'if this may benefit healthcare'. It is not clear which individuals would make this judgement, and once outside the walls of the Information Centre, who knows where it could end up?

• Legal approval to use identifiable personal data could be granted if it is deemed to be in 'the interests of patients or the wider public to do so' and it is 'impractical to obtain each patient's consent' and 'not possible to use anonymized data'.

• A revised, small-scale roll-out involving data from 100–500 general practices is planned for autumn 2014, which is right now! So how the issues raised so far by members of the public will be taken into account is not clear.

• We have no idea how much this will all cost.

My view

I will not object to my data being captured in this scheme. The balance of risk to the individual versus the benefit to everyone seems to me to be in favour of benefit. I do feel, however, that patients should be given the option of 'opting in' rather than 'opting out'.

More information can be accessed through the web page www.england.nhs.uk/ourwork/tsd/care-data and individuals can express their views on care.data by e-mailing england.cdo@nhs.net.

Flu season 2014/15

Seasonal immunization clinic

We offer you jabs to protect you against:

- Flu
- Halloween
- Christmas

If only ... *by Tim Hughes*

This year's Nuffield Practice Flu Clinics started on Tuesday 30 September. We will also be running a clinic on Saturday 18 October to accommodate those of you who cannot attend during the week.

The Nuffield Practice will not be sending out letters inviting you for a flu jab. Please contact the Practice to book your appointment if you have had a flu jab in previous years and/or if you fall into one of the groups below:

- patients aged 65 years or older
- patients aged 6 months or older who have any of the following:
  - chronic respiratory disease
  - chronic heart disease
  - chronic kidney disease
  - chronic liver disease
  - chronic neurological disease
  - diabetes
  - immunosuppression
- pregnant women at any stage of pregnancy
- carers
- children aged from 2 to 4 years.

Nuffield Practice Patient Survey

The Practice will be running its annual patient survey throughout November. The survey will be available on the Nuffield Practice website and, if you visit the Practice, also as hard copy.

This is an important opportunity to have your say on the things that are important to you in the Practice, so please fill in a copy. If you care about what questions are going to be asked, come along to the next meeting of the Patient Participation Group!

Let us contact you by e-mail

At the moment, we are not able to send copies of the survey by e-mail because we need your permission to do that. If you would like the Nuffield Practice to contact you by e-mail for the survey and for other relevant Practice needs, please contact the reception staff (preferably e-mail Catherine Simonini, Practice Manager, catherine.simonini@nhs.net).

Let us contact you by text message

Similarly, it would help the administration of the Practice very much if we could contact you by text to attend your annual reviews and immunizations, but again we need your permission. Please pick up a form at Reception and fill it in before you leave.

More Nuffield Practice news

Ask the Nurse!

Please remember that our Practice Nurses can offer the following services and advice: Smoking Cessation, Travel Immunizations, Contraception and Weight Loss Referral.

Get a *Chlamydia* test!

If you are aged 15–25 years and sexually active, please ask your doctor or nurse for a *Chlamydia* testing kit. *Chlamydia* is one of the most common causes of sexually transmitted infections in the UK. Most people who have a *Chlamydia* infection don't notice any symptoms, and so you may not know if you have it. Testing is free and easy and only takes a couple of minutes.

My Story

by Robert Owen

In 2007, my wife and I had a fabulous fly–drive holiday in Nova Scotia and Prince Edward Island. During the holiday, I suffered some occasional pains which I put down to indigestion. About 3 weeks later, when I was going to bed, I went to lie down when I shot up in intense agony.

Unable to lie down, I spent the next 10 nights in a rocking chair because that was the only way to reduce the pain. During those 10 days, I swallowed many pills for 'constipation' following a provisional diagnosis, but nothing reduced the pain or helped me with my problem.

When my usual doctor returned from holiday he took one look at me and had me admitted to the John Radcliffe Hospital.

There, I had a CT [computed tomography] scan but only managed a few moments lying down in the scanner and was completely shattered afterwards from the pain.

The following day, I was sent again for a CT scan and I was told I would spend 15 minutes lying face down. The scanner nurse, like my GP, recognised how much pain I was in and arranged for the scan to be re-scheduled and instructed the ward to give me sufficient pain killers, which duly happened.

After the successful scan, things moved quickly. I was told that I had aggressive non-Hodgkin lymphoma in three places. I was quickly moved to the haematology ward, where I started chemotherapy. Later, my consultant said that if treatment had been delayed by a few days I might have died.

There is a funny side. While the nurse was putting the chemo into my body, I had a bottle under a sheet collecting water from my body. I think I filled six or seven bottles. Immediately after the first chemo, I had no more pain.

Fortunately, after having six sessions of chemo and 3 years of aftercare, I was discharged last July as being in full remission. However, the illness and possibly also the chemo have left me with a balance and mobility problem.

The care I received from the haematology consultants, nurses, ancillary staff and my GP was absolutely superb. Looking back, I feel frustrated that the correct diagnosis took so long. However, I now understand that many serious diseases like non-Hodgkin lymphoma can cause a wide range of non-specific symptoms making it difficult for doctors to tell them apart from less serious and more common conditions. This is why certain conditions are usually diagnosed 'late'. Two thirds of non-Hodgkin lymphomas are diagnosed at a 'late' stage as in my case. I am told that pain at night, such as I had, would be the one symptom that might have alerted doctors to a serious problem at an earlier stage. I can also see the value of having a long-term relationship with a GP so that they know when a person has symptoms that are 'unusual for them' and so might heed them all the more closely.

There are a number of things that helped me through that difficult time, for which I am grateful. There was the support of my wife, children and grandchildren, my friends and my church. I received many emails, cards, letters and phone calls from all around the world, which was encouraging. Finally, I read much about lymphoma, but there is one book that stands out: *A Reason for Hope* by Michael Barry. This I found particularly helpful and I have loaned it out many times since.

Sustainable GP practice in Oxfordshire

by Graham Shelton

This is a personal perspective and not necessarily the view of the Nuffield Partners.

There is important work going on nationally and at the Oxfordshire Clinical Commissioning Group (OCCG) on the vision, strategy and action plan needed to support general practice now and in the next 5 years. Everyone in our Practice will have the chance to contribute.

The work recognizes the challenges facing general practice, ranging from changes in population, increases in need, workload, stress and financial pressures, a changing workforce profile and changes in public expectations.

General practice: a call to action

This NHS England initiative (see www.england.nhs.uk/ourwork/qual-clin-lead/calltoaction/igp-cta) concluded that clinical commissioning groups need to work locally to deliver six core objectives:

- provision of holistic care
- fast, responsive access to care
- promotion of health and wellbeing, reducing inequalities and preventing ill-health
- personalization of care by involving patients more fully in managing their own care
- operation at greater scale whilst preserving the strengths of continuity of care and relationships with local communities
- working as a more integrated part of a wider set of community-based services.

OCCG public consultation to date

The OCCG has stated that 'the transformation of primary care' is a priority, and it is therefore setting out to answer the following questions.

1. What are the strategic priorities for supporting general practice in Oxfordshire, from both the patient and the practitioner perspectives (what is good and what needs to change)?

2. What are the causes of increased workload in general practice and what actions are needed to address these? Among the causes identified so far are: patient expectations, care homes, practices themselves, NHS 111, prescribing, district nursing, secondary care, social care and commissioning.

3. What are the opportunities for OCCG to commission from primary care in order to address these needs?

Early findings

The strengths of general practice need to be preserved

- Continuity of care is very important: people wish to keep their named/personal doctor.
- The role of Practice Nurses is highly valued.
- Flexibility of access, including use of e-mail advice and telephone consultations, is supported and there is a desire for this to be available in all surgeries.
- Some practices operate as information hubs for other services, and this is particularly valued in rural communities.

Some changes are needed

- Patients need improved access to care, including shorter waiting times to see a familiar GP (waits of up to 5–6 weeks are reported).
- In general, patients in Oxfordshire are willing to see other GPs in order to receive urgent same-day treatment not related to a long-term condition.
- Support for carers needs to improve.
- Reception/admin staff could and should take on a greater signposting function.

What OCCG will do next

We've barely started the journey, and it will require a great deal of patient and doctor input.

Your contribution

If you have any views on what we should do from a patient perspective, do please get in touch either with the Nuffield PPG (via catherine.simonini@nhs.net) or with me as West Locality Public and Patient Forum Chair (graham.shelton@pharmagenesis.com). I will make sure that every piece of patient input is fed into the system.

Evidence Matters

by Sarah Chapman

I work for the Cochrane Collaboration, an international network of people working together to help people make informed decisions about health care. It does this through doing systematic reviews, which bring together the results of clinical trials to answer questions about what helps or harms in health care.

Women, wetting and what you can do

Do you leak when you laugh or sneeze? If so, you may be one of the many women experiencing stress urinary incontinence.

Stress urinary incontinence happens when weaknesses in the structures supporting the bladder, chiefly the pelvic floor muscles, fail to stop urine leaking out when the bladder is under pressure.

It's not talked about much but, ladies, you need to know that you're not alone, that leaking's not normal, and that there's a good chance of improvement. So what, and who, can help?

Well, you can, and pelvic floor exercises are the thing. Pregnancy and birth do not do pelvic floor muscles any favours and this is often the time we're told to do pelvic floor exercises, clenching and relaxing these muscles.

Doing pelvic floor exercises is the most usual treatment for women with SUI and can help all of us keep our pelvic muscles in good working order!

I suspect that most of us soon abandon the effort, but we should be doing these exercises every day.

Do you need convincing that they are worth it? Good evidence from a Cochrane review showed that, compared with similar women not doing pelvic floor exercises, women doing them:

- were 8 times more likely to report being cured and 17 times more likely to report cure or improvement
- leaked smaller amounts and needed the loo less often
- found benefits for sex
- rarely had any ill effects and these were minor when they did happen.

Clinical guidelines say these exercises are best taught one to one, but there aren't enough health practitioners available to do this for everyone. If you want to find out about them online, there's helpful information at www.pelvicfloorfirst.org.au, which also has a useful app that you can download.

You can see the review in full at www.thecochranelibrary.com or go to http://summaries.cochrane.org and look for 'pelvic floor exercises' to see lots of reviews on this.

Dumoulin C, Hay-Smith EJC, Mac Habée-Séguin G. Pelvic floor muscle training versus no treatment, or inactive control treatments, for urinary incontinence in women. Cochrane Database of Systematic Reviews 2014, Issue 5. Art. No.: CD005654.

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You can access these articles at www.thenuffieldpractice.co.uk

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