

Providing Information, choices and alternatives to prescription medicine

Health Overview & Scrutiny Committee

Date: 2 April 2014

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| Author: | HOSC Members Cllr W. Crabbe, Cllr J. Wright and Cllr R. Wright |
| Wards: | All Wards |
| Locality Affected: | All Localities |
| Parishes Affected: | All Parish Areas |

1. Purpose and Reasons

- 1.1 At its meeting on the 5th June 2013, the Health Overview and Scrutiny Committee agreed to the inclusion of a report in to its work programme for 2013-14 on Alternative and Complimentary medicine. This report would be prepared by a select few Members of the Committee hereinafter referred to as the Working Group.
- 1.2 The purpose of the report is to provide the Health Overview and Scrutiny Committee with an opportunity to discuss the possible side effects of prescribed drugs and explore how alternative and complimentary medicine could help some patients.
- 1.3 It also aims to highlight the Health Inequality created by not commissioning access to Complimentary or Alternative treatments within the NHS provision.
- 1.4 All Residents in Swindon should be given the option to avoid the side-affects of prescription drugs and not just those who can afford to pay privately. Everyone should be provided with the information to make an informed choice.
- 1.5 To help recognise that whilst at least three opportunities (GP Surgery, Doctor, Pharmacist) exist to help patients understand the side affects of prescription medicine, many patients are not aware of their rights or participate in a choice as an option.
- 1.6 This report by the working group aims to assist and broaden local commissioners awareness in providing local choice and personal control of budgets so patients have the option to choose complimentary or alternative treatment as an alternative to prescription medicines.
- 1.7 Learn from the experience of other Trusts such as Bristol CCG to help speed up any changes recommended.

Providing Information, choices and alternatives to prescription medicine

Health Overview & Scrutiny Committee

Date: 2 April 2014

- 1.8 To find out why other Trusts find it possible to inform patients about the side effects of harmful prescription medicines and provide Complimentary or Alternative treatments.
- 1.9 To look at providing equal access to Complimentary or Alternative treatments.
- 1.10 To find better ways for patient rights to be communicated without delaying treatment.

2. Recommendations

The Committee is recommended to:

- 2.1 Pass this report and the Committee's comments to the Cabinet Member for Health and Adult Social Care and the Health and Wellbeing Board, to promote the access to information on alternative and complimentary medicine with the Swindon Clinical Commissioning Group.

3. Detail

Background

- 3.1 The Chief Executive of the Health Service signed a document entitled "*The NHS Belongs to the People. A Call to Action*"
- 3.2 It begins with the statement that *the NHS is more than a system: it is an expression of British values of fairness, solidarity and compassion*. It also states "Doing nothing is not an option" – The NHS cannot meet future challenges without change.
 - "*Even low levels of adverse events are far too high*" Of those people who do experience adverse events, a third of them experienced a greater disability or death.
 - *The 30% who have one or more long term conditions account for £7 out of every £10 spent on health and care in England.*
 - *The evidence shows that when patients are involved in managing and deciding about their own care and treatment, they have better outcomes, are less likely to be hospitalized, follow appropriate drug treatments and avoid other treatment.*
 - "*Patients should have the same levels of access, information and control over their healthcare matters as they do in the rest of their lives*"

Providing Information, choices and alternatives to prescription medicine

Health Overview & Scrutiny Committee

Date: 2 April 2014

- *“Better management by patients will mean fewer hospital visits and lower costs to the NHS overall”*
- 3.3 *In the report “Improving General Practice – A Call for Action” by Tanya Rowan and Jonathan Gordon Research Advisor and Research Manager CIPFA Research January 14*
- 3.4 The Patients and service users, London state:-
- “I do not want choice. I want a local GP practice and hospital which provides all care.”*
- It has to be question why in Swindon this goal is not available or being worked towards.
- Reason why Change is needed
- 3.5 It is estimated that 150,000 patients a year die in Europe from taking prescription medication as prescribed. 23% of European Citizens claim to be affected by medical error. 18% experienced a serious error in Hospital with 11% being prescribed the wrong medication. In the UK around 10% Hospitalisations are due to medical errors. Infections associated with Health Care in the UK are estimated to cost £1 billion per year. (WHO website Data & Statistics Population Europe 739 m UK 65 m).
- 3.6 A Patients choice consideration is a harm reducing opportunity. This could have helped to reduce the health effects on 81.29 million patients across Europe.
- 3.7 Patients taking care of themselves is the most cost effective way of improving Health and reducing demand. Some conditions require medical treatment and the relationship with the medical profession becomes interdependent, with the patient trusting the medical practitioner to make the right choice. The limited options and reliance on prescription medicines in the Swindon area reduces both the practitioners and patients choice of safer Complimentary or Alternative treatment.
- 3.8 RxISK (Independent global prescription safety fund) Chief Medical Officer Dr. Dee Mangin puts it, “Prescription drug side effects are now a leading cause of death, disability, and illness along with cancer, heart disease and stroke.” RxISK CEO Dr. David Healy adds, “In mental health care, drug side effects are the leading cause of death.”
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Providing Information, choices and alternatives to prescription medicine

Health Overview & Scrutiny Committee

Date: 2 April 2014

- 3.9 Ben Goldacre wrote the book *Bad Pharma* because of the need to fix a set of problems which have been allowed to persist in Medicine for too long. In his view the problems have a real impact on patient care. As a Doctor he questions why these problems have been able to persist so long especially as they are routinely documented in academic literature. More to the point he states the problem is fixable.

Government Submission

- 3.10 Last September (2013) the House of Commons Science & Technology Committee issued a report on clinical drug trials in which the Chair, Andrew Miller MP stated:-

“Many of the trials taking place today are unregistered and unpublished, meaning that the information that they generate remains invisible to both the scientific community and the public. This is unacceptable, undermining public trust, slowing the pace of medical advancement and potentially putting patients at risk.

We consider that all trials conducted on NHS treatments—and all other trials receiving public funding—should be prospectively registered and their results published in a scientific journal. While the focus should be on implementing this change for future trials, the Government must also do what it can to ensure that historic trials are registered and published, particularly where they have been publically funded.”

- 3.11 A report in July 2005 by the Science & Technology Committee entitled “The Influence of the Pharmaceutical Industry” questioned the ability of the pharmaceutical industry’s ability to put patients’ health before the needs of their shareholders’ interests. It described the influence of the pharmaceutical industry as pervasive and persistent – impacting on research, regulators, the media and politicians. The committee recommended research should be undertaken into not only the adverse effects of drugs but also into the costs of drug –induced illness and the effects of multiple drug use. The committee also pointed out that there is little independent research comparing drug and non-drug approaches to health care and that research which is not in the interest of the pharmaceutical industry should be funded by the government. Unfortunately it appears that advice was not acted upon.

Please refer to Appendix 1 for further comments by the Working Group on various Government reports.

Medical Reports

Further information on the subject of this report can be obtained from Sally Smith, 01793 463412, ssmith3@swindon.gov.uk.

Providing Information, choices and alternatives to prescription medicine

Health Overview & Scrutiny Committee

Date: 2 April 2014

- 3.12 A report by the BMJ last June (2013) reported that a group of doctors called for all unpublished and misreported trials to be published or formally corrected within the next year to ensure doctors and patients are able to rely on complete and accurate information to make decisions about treatment. Around half of all clinical trials for medication in use today have never been published. The report states a whole range of drugs have been falsely represented as safer and more effective than they actually are, putting patients at risk and wasting public money. Freedom of Information reports have established that the authors of the report have access to 178,000 pages of previously confidential trial documents and clinical study reports for widely used drugs which they will make available if the drug companies fail to comply.
- 3.13 Another BMJ report published last October (2013) refers to an estimated 250,000 people who have been exposed to the risks of trial participation without societal benefits that accompany the dissipation of trial results. This was described as a “violation of an ethical obligation”.

Please refer to Appendix 2 For further comments by the Working Group about medical evidence.

The Working Group’s view on Human Rights Issues

- 3.14 Human Rights legislation includes the Right to Life. This prohibits cruel and degrading treatment. The working group have concerns that some patients may, in contravention of this Right, patients are being prescribed inadequately tested medication and some are unknowingly being used as guinea pigs, usually without recourse to compensation. 3.14 The Human Rights Act places a duty on Swindon Borough Council to respect all Rights when delivering services. The Health and Social Care Act 2012 includes a duty to involve patients and the public in the commissioning of services. The view of the Working Group is that the existing practice continues to go against the recommendation of the Department of Health which has chosen NHS Somerset to develop pioneering strategies for public and patient involvement. NHS Somerset funds Homeopathic activity at the Bristol Homeopathic Hospital, as does NHS Bristol, NHS South Gloucestershire and NHS Banes. NHS Somerset further provides funding to the Glastonbury Health Centre to support musculo-skeletal services which include osteopathy and acupuncture.

Please refer to Appendix 3 at the back of this report for further comments by the Working Group on Human Rights issues.

The Working Group’s view on Financial Grounds for change

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Providing Information, choices and alternatives to prescription medicine

Health Overview & Scrutiny Committee

Date: 2 April 2014

- 3.15 Almost half of the adult population of the UK will report low back pain at some time in the year, with four out of five experiencing back pain at some point in their lives. This increases with advancing age with up to 7% of people with acute back pain developing a chronic condition. The NHS spends more than £1bn per year on back-pain related costs. Nearly 5 million working days are lost as a result. Nearly 4% of back pain sufferers consult their GP while 10% visit osteopaths, chiropractors or acupuncturists. Between 1996-1999 a study carried out by the Wiltshire Health Authority showed that 83% of patients receiving alternative care were better after treatments, had high satisfaction rates, with reduced costs for the NHS. One GP practice saved approx £10K in one year from a reduction in referrals to hospitals. In line with Nice guidelines CG88, the North East Essex project has shown a reduction of costs to the NHS and referrals to spinal surgeons of 25%. Many patients in Swindon never get to experience the benefits of these treatments because they simply cannot afford to pay privately.
- 3.16 The Role of Complimentary and Alternative Medicine (CAM) in the NHS, led by Christopher Smallwood, concludes that for some treatment significant savings can be made. This report highlights where conventional medicine is not responding adequately to the needs of patients and the effectiveness gap can be filled by CAM. (This report is detailed and informative about various aspects of CAM in the NHS).

Limiting Swindon's Choice

- 3.17 Swindon's stated vision and aim is "Delivering excellence for Swindon by adding life to years and years to life". The promise is to:

Drive out inequality in health and wellbeing.

Drive up service quality and access to care

Give people more influence, choice and control over their lives.

- 3.18 Under the heading of Equality, Diversity and Accessibility the Swindon CCG undertakes to reduce variation in service experience, promote human rights outcomes for patients, carers and staff by implementing the Equality Act 2010 and by making reasonable adjustments to local health services of members of equality groups. The Working Group's view is that to date this has clearly not been the experience of many Swindon residents and CAM's are only available to those patients who are able to pay privately.

The Working Group's view on Swindon's Limited Offer

Providing Information, choices and alternatives to prescription medicine

Health Overview & Scrutiny Committee

Date: 2 April 2014

- 3.19 The Working Group's view is that in Swindon only conventional medicine is available and that all avenues to Alternative treatment have been withdrawn without consultation.
- 3.20 The Working Groups view, in contravention of S242 of the NHS Act, access to the Bristol Homeopathic Hospital by Swindon patients was withdrawn without patient consultation and without first showing the difference to the benefit of patients. It is understood that the PCT restricted access in 2009.

Need for Understanding and Change

- 3.21 Few people in Swindon are aware of these various findings and recommendations made by the House of Lords and the Commons. The Working Group's view is that it is imperative that all of this information is readily available on the council website as part of our Duty of Care to allow residents to make the changes *and informed* choices NHS England is calling for – as per their vision statement - High quality care for all, now and for future generations.

4. Alternative Options

- 4.1 Continue with what the Working Group believe to be the existing harmful practices
- 4.2 Implement only part of the recommendations

5. Implications, Diversity Impact Assessment and Risk Management

Financial and Procurement Implications

- 5.1 There are no financial considerations arising from the recommendations of this report

Legal and Human Rights Implications

- 5.3 Legal and Human rights considerations in the view of the Working Group form part of the grounds for change.

All Other Implications (including Staff, Sustainability, Health, Rural, Crime and Disorder)

- 5.4 This report highlights that in the view of the Working Group, in spite of the best evidence which support and can improve Health Outcomes there is a reluctance to change. Whilst some reports in the Working Groups view are blatant about drug company vested interests there are also difficulties with patient

Providing Information, choices and alternatives to prescription medicine

Health Overview & Scrutiny Committee

Date: 2 April 2014

understanding, health professional availability, closed minds and change being resisted due to a range of other pressures stemming from NHS transformation.

The Working Group believes that there are strong and proven links between prescription medicines and side affects. The Health Profession acknowledges this and tries to regulate and control the affects. Drug compatibility and assessment could be aided if alternative or complimentary medicines were part of the patient choice options. Supporting choice can assist improving Health outcomes

Under the heading of Equality, Diversity and Accessibility the Swindon CCG undertakes to reduce variation in service experience, promote human rights outcomes for patients, carers and staff by implementing the Equality Act 2010 and by making reasonable adjustments to local health services of members of equality groups. The Working Group believe that to date this has clearly not been the experience of many Swindon residents and that CAM's are only available to those patients who are able to pay privately.

Links to One Swindon, Plans and Policies

- 5.5 One Swindon Priority – Living independently, protected from harm, leading healthy lives and making a positive contribution.

Diversity Impact Assessment

- 5.6 A Diversity Impact Assessment has not been completed at this stage.

Risk Management

- 5.7 The Working Groups view is that there is a risk that:-
- Some Health professionals may not have been fully trained in the benefits of CAM treatments and services.
 - Safe Complimentary or Alternative medicine/services may take some time to be approved and listed and the potential for harm from Medicine remains the same.
 - There is risk that the “Effectiveness Gap” will remain if the Chief Executive of the Health Service Call for Action and Change is not locally supported
 - Important authoritative voices have spoken out for the need of patients to take control and be more responsible for their own health outcomes unfortunately many rely on others and this will allow the harmful paradigm

Providing Information, choices and alternatives to prescription medicine

Health Overview & Scrutiny Committee

Date: 2 April 2014

to remain unless the CAM choices are consistently communicated and provided to patients.

- Members may have limited insight into the subject matter being reported and may be comfortable with the existing paradigm. Unless an initiative is taken, this lack of understanding could prevent a new paradigm being developed.

6. Consultees

- 6.1 The Director of Finance (Section 151 Officer) and Director of Law and Democratic Services (Monitoring Officer) are consulted in respect of all reports.

7. Background Papers

The Role of Complimentary and Alternative Medicine (CAM) in the NHS led by Christopher Smallwood

8. Appendices

Appendix 1 – Working Groups views on Government Reports

Appendix 2 – Working Groups views on Medical Evidence

Appendix 3 – Working Groups views on Human Rights

Providing Information, choices and alternatives to prescription medicine

Health Overview & Scrutiny Committee

Date: 2 April 2014

Appendix 1. Working Groups view on Government Reports

The report of the House of Lords Select Committee 6th Report has been selectively edited to deny patients in Swindon access to CAMS. However there is much in the report which suggests that the following has not been brought to public awareness in Swindon as follows:

They noted that CAM is available on the NHS, and has been since its inception. A study by the Department of Health in 1995 reported that 40% of GP partnerships in England provide access to CAM for NHS patients. But this provision is very patchy - whether patients have NHS access to CAM is dependent on the attitude of their particular PCG or Primary Care Trust (PCT)[

The report included a report by The Marylebone Health Centre which developed a list of conditions that they commonly consider for CAM referrals. These include complex chronic illnesses such as: chronic fatigue syndrome; stress-related conditions; asthma; irritable bowel syndrome; eczema and non-specific allergies; back pain and migraine. GPs at the Centre consider a referral if there is an initial diagnosis of one of these conditions and if one of the following criteria applies: (a) conventional medicine has failed; (b) the patient is suffering side-effects from the conventional treatment; (c) the patient requests CAM for one of the conditions above; or (d) if the GP feels it is a complex case where a CAM may help (and having asked the CAM therapist they, too, feel they may be able to help.)

The recommendations of the committee included that if a therapy gains a critical mass of evidence to support its efficacy, then the NHS and the medical profession should ensure that the public have access to it and its potential benefits

They further recommended that familiarization should prepare medical students for dealing with patients who are either accessing CAM or have an interest in doing so. This familiarization should cover the potential uses of CAM, the procedures involved, their potential benefits and their main weaknesses and dangers.

Providing Information, choices and alternatives to prescription medicine

Health Overview & Scrutiny Committee

Date: 2 April 2014

Appendix 2 Working Groups view on Medical Evidence

Another BMJ report published last October (2013) refers to an estimated 250,000 people who have been exposed to the risks of trial participation without societal benefits that accompany the dissipation of trial results. This was described as a “violation of an ethical obligation”.

This was graphically illustrated in a recent Panorama program entitled “The Truth about Pills and Pregnancy”. The program focused on Epilim - a drug prescribed for epilepsy, bi-polar disease, depression, blood pressure and headaches. It is a known teratogen (known to cause malformation to an embryo or foetus; capable of interfering with the development of a foetus; causing birth defects) and may result in multiple birth defects, dimorphic faces, developmental delay, learning difficulties and/or behavioural problems. Approximately one in 250 pregnancies is known to be exposed to anti-epileptic drugs and a significant proportion – up to 40% - of those are exposed to valproate which may result in Sodium Valproate Syndrome. In children the risks may include spina bifida, cleft palate, autism, asthma, bowel problems, joint pain, sleep problems, sensory issues, and problems with memory, concentration and attention. There is an increased rate of admission to Special Care Baby Units due to withdrawal symptoms and major malformations. Withdrawal symptoms may present as feeding difficulties, hypoglycaemia, jitteriness, irritability and hypothermia and are seen frequently in the early postnatal period. The affected babies are often noted to be floppy with poor muscle tone and joint laxity. The risk of a limb abnormality from VPA exposure has been estimated to be about 0.42%. It has been reported that the IQ of the child may be affected if surgical intervention is not offered before the age of 6 months. In general, the most frequently affected developmental aspect is speech and language. There is a delay in both the comprehension and expression of speech and language resulting in the need for speech therapy.

It has been prescribed for 40 years. Although the side effects were first reported in 1984 it is still being prescribed. It is estimated that the number of affected children is growing by 1354 each year. There are more children affected by Sodium Valproate than Thalidomide. Many children will require surgery and constant care, sometimes for the entire duration of their life. The cost to society is enormous. The distress and suffering to affected families is beyond measure, with both parents may be forced to give up work to care for children. Every one's Right to a normal family life is affected

NHS Choices details on Epilim note that 1 in 100 patients may commonly experience any of 22 listed side effects. There are a further 14 side effects which may be experienced by 1 in 1000 patients. Listed as “rare” – 1 in 10,000 are 13

Providing Information, choices and alternatives to prescription medicine

Health Overview & Scrutiny Committee

Date: 2 April 2014

side effects. **In total there are 50 possible side effects but no mention at all of the high risk of stillbirths, miscarriage, perinatal mortality or foetal abnormalities.**

They went on to recommend that every medical school ensures that all their medical undergraduates are exposed to a level of **Complimentary and Alternative Medicine (CAM)** familiarization that makes them aware of the choices their patients might make and that the NHS Centre for Reviews and Dissemination work with the RCCM, the UK Cochrane Centre, and the British Library to develop a comprehensive information source with the help of the CISC database, in order to provide comprehensive and publicly available information sources on CAM research, and that resources be made available to enable these organizations to do so. Swindon has no such information generally available to patients.

Where delivery is concerned they saw the NHS as the natural home in the United Kingdom for reliable, non-promotional information on all types of healthcare; providing a home is particularly important for CAM, where the diversity of opinion and organizations make it almost impossible for individuals to gain an overview. They supported the plans of the Department of Health to make information on CAM available through NHS Direct, and urged that they be carried out in the very near future.

They recommended that those practicing privately-accessed CAM therapies should work towards integration between CAM and conventional medicine. They urged CAM practitioners and GPs to keep an open mind about each other's ability to help their patients, to make patients feel comfortable about integrating their healthcare provision and to exchange information about treatment programs and their perceptions of the healthcare needs of patients.

Providing Information, choices and alternatives to prescription medicine

Health Overview & Scrutiny Committee

Date: 2 April 2014

Appendix 3. Working Groups view on Human Rights

The Human Rights Act is fundamental to all NHS policies including the NHS Constitution, The NHS Consent to Treatment Policy and the Choose and Book System. All patients have a Right to physical and psychological integrity. Further Rights include the Right to public health services and the Right to freedom of religious thought and belief. Secular thinking may not be forced onto those Swindon residents who believe that restoring the balance of energy meridians in the body is the key component to physical health. Any treatment that affects the physical body will also affect the mind and consequently the energy field. Allopathic medicine is often detrimental to the body's inherent ability to heal itself. These Rights are denied when patients are excluded from making decisions about their choice of safe, effective healthcare.

The Human Rights Act places a duty on Swindon Borough Council to respect all Rights when delivering services. The Health and Social Care Act 2012 includes a duty to involve patients and the public in the commissioning of services. The existing policy continues to go against the recommendation of the Department of Health which has chosen NHS Somerset to develop pioneering strategies for public and patient involvement. NHS Somerset funds Homeopathic activity at the Bristol Homeopathic Hospital, as does NHS Bristol, NHS South Gloucestershire and NHS Banes. NHS Somerset further provides funding to the Glastonbury Health Centre to support musculo-skeletal services which include osteopathy and acupuncture.

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Providing Information, choices and alternatives to prescription medicine

Health Overview & Scrutiny Committee

Date: 2 April 2014

other symptoms without respite. The lack of choice of treatment means they are forced to place themselves at risk of possible side effect, an increasing amount of differing medication, each countering previous side effects and in some cases an early death. There is also increasing evidence of a link between anti-depressants and suicide.

Human Rights legislation includes the Right to Life. This prohibits cruel and degrading treatment. In contravention of this Right, patients being inadequately tested prescription medication are unknowingly being used as guinea pigs, usually without recourse to compensation. Another BMJ report published in October refers to an estimated 250,000 people who have been exposed to the risks of trial participation without societal benefits that accompany the dissipation of trial results. This was described as a “violation of an ethical obligation”.

This was graphically illustrated in a recent Panorama program entitled “The Truth about Pills and Pregnancy”. The program focused on Epilim - a drug prescribed for epilepsy, bi-polar disease, depression, blood pressure and headaches. It is a known teratogen (known to cause malformation to an embryo or foetus; capable of interfering with the development of a foetus; causing birth defects) and may result in multiple birth defects, dysmorphic faces, developmental delay, learning difficulties and/or behavioural problems. Approximately one in 250 pregnancies is known to be exposed to anti-epileptic drugs and a significant proportion – up to 40% - of those are exposed to valproate which may result in Sodium Valproate Syndrome. In children the risks may include spina bifida, cleft palate, autism, asthma, bowel problems, joint pain, sleep problems, sensory issues, and problems with memory, concentration and attention. There is an increased rate of admission to Special Care Baby Units due to withdrawal symptoms and major malformations. Withdrawal symptoms may present as feeding difficulties, hypoglycaemia, jitteriness, irritability and hypothermia and are seen frequently in the early postnatal period. The affected babies are often noted to be floppy with poor muscle tone and joint laxity. The risk of a limb abnormality from VPA exposure has been estimated to be about 0.42%. It has been reported that the IQ of the child may be affected if surgical intervention is not offered before the age of 6 months. In general, the most frequently affected developmental aspect is speech and language. There is a delay in both the comprehension and expression of speech and language resulting in the need for speech therapy.

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Providing Information, choices and alternatives to prescription medicine

Health Overview & Scrutiny Committee

Date: 2 April 2014

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