

Health and Social Care Committee

Meeting Venue:

Committee Room 1 – Senedd

Meeting date:

Wednesday, 26 March 2014

Meeting time:

10.30

Cynulliad
Cenedlaethol
Cymru

National
Assembly for
Wales



For further information please contact:

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Committee Clerk

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Agenda

Private

The Committee agreed on 20 March 2014, a motion under Standing Order 17.42 to resolve to exclude the public from items 1 and 2 of the meeting

1 Consideration of the Committee's work plan for the inquiry into progress made to date on implementing the Welsh Government's Cancer Delivery Plan (10:30 – 10:45) (Pages 1 – 10)

2 Consideration of the Committee's forward work programme for summer term 2014 (10:45 – 11:00) (Pages 11 – 22)

2.1. Forward work programme for summer term 2014.

2.2. Letter from the Deputy Minister for Health and Social Services to the Chair regarding the Social Services and Well-being (Wales) Bill eligibility technical panel.

Public

3 Introductions, apologies and substitutions

4 Inquiry into the availability of bariatric services: Evidence session 2 (11:00 – 12:00) (Pages 23 – 36)

Mark Drakeford AM, Minister for Health and Social Services

Dr Sarah Watkins, Head of Mental Health and Vulnerable Groups Division, Welsh Government

Chris Tudor-Smith, Head of Health Improvement Division, Welsh Government

5 Papers to note

Additional information from the meeting on 13 February 2014 (Pages 37 – 41)

Note taken at the working lunch with Swansea University academics, 13 February 2014 (Pages 42 – 47)

Note taken at the meeting with Welsh Institute of Metabolic and Obesity representatives, 13 February 2014 (Pages 48 – 51)

Note taken at the focus group event, Cwmbrân, 12 March 2014 (Pages 52 – 59)

Correspondence from the Royal College of Nursing Wales – suggested inquiry into Community Nursing (Pages 60 – 66)

Correspondence from Crohn's and Colitis UK – suggested inquiry into the implementation of national guidance on Inflammatory Bowel Diseases (IBD) (Pages 67 – 72)

Agenda Item 1

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Gwenda Thomas AC / AM
Y Dirprwy Weinidog Gwasanaethau Cymdeithasol
Deputy Minister for Social Services



Llywodraeth Cymru
Welsh Government

Ein cyf/Our ref: LF/GT/0231/14

David Rees AM
Chair, Health and Social Care Committee
National Assembly For Wales
Cardiff Bay
CF99 1NA

5 March 2014

Dear David,

Social Services and Well-being (Wales) Bill - Eligibility Technical Group

I am writing to you enclosing two documents for the Committee's attention. These are:

- a copy of my letter dated 18 February 2014 to the members of the Technical Group on Eligibility; and
- a copy of the membership list for the Group.

The Group has been established to make recommendations as to the needs, circumstances and outcomes which should form the basis of an enforceable right to care and support, as provided for in sections 28, 31, 33, 36 and 37 of the Social Services and Well-being (Wales) Bill (as amended at Stage 3). These will inform the development of a national eligibility framework, underpinned by Regulations as required by section 28 and 29 of the Bill and by a Code of Practice issued under section 139.

With representation from key stakeholders including statutory bodies and third sector organisations, the first meeting of the Group took place on 19 February and was well attended. The final meeting of the group will take place in early April, to be followed by one or more national stakeholder engagement events in May which will test and explore the Group's findings. These events will be facilitated by the Social Services Improvement Agency. I expect to receive a final report from the Group following those events in order that the draft Regulations and Code of Practice can be put out to consultation in late spring.

In my written statement of 5 November 2013 I made a commitment to refer the draft Regulations and Code to the Committee at the point at which the public consultation commences. Through this letter I am re-stating my commitment to do this.

Yours sincerely

Gwenda

Gwenda Thomas AC / AM
Y Dirprwy Weinidog Gwasanaethau Cymdeithasol
Deputy Minister for Social Services

Bae Caerdydd • Cardiff Bay
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Wedi'i argraffu ar bapur wedi'i ailgylchu 100% **Page 18**

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Ein cyf/Our ref: LF GT 194 14

To all members of the Technical
Group on Eligibility

18 February 2014

Dear Group Member

I would like to take this opportunity to thank you for the contribution you are making to the Technical Group on Eligibility. The work of the group will assist officials to provide advice to me on the Regulations and Code of Practice for determining eligibility for care and support services under the Social Services and Well-being (Wales) Bill.

The design of the new eligibility process is fundamental to delivering the overall changes to the system of care and support that are provided for through the Social Services and Well-being (Wales) Bill. Your task is to advise on the process that most enables statutory services to meet their overarching duty to promote the well-being of people who need care and support.

I expect the Bill's definition of well-being to be the starting point in your work. Taking full account of each of the individual elements that make up that overall definition will enable you to scope out the new framework such that it becomes embedded in the overall purpose of the Social Services and Well-being (Wales) Bill, and in the duties to individuals that the Bill introduces.

I am seeking a national framework for eligibility that will be consistently applied across Wales so that people know with confidence that their care and support needs will be met. The new system must ensure people and families get the right support, in the right place, at the right time.

The Social Services and Well-being (Wales) Bill places on-going responsibilities on local authorities to look at wider support across the new care and well-being system to ensure that a greater number of people with needs are supported in a range of ways that can be accessed outside the eligibility criteria

Whilst assessment and eligibility will play an integral role in the new system, the significance that the eligibility decision will have on whether an individual receives care and support to meet their needs will be considerably reduced - many more people will be supported

through the general duties placed on local authorities, without the triggering of a statutory duty to provide support.

I am seeking your advice on the model of eligibility that most supports and promotes people's access to community based, preventative and early intervention services and, **at the same time**, ensures that services are provided to those who need significant support and help with their personal care; and through this help, are supported to retain control over their day to day lives.

However, I want group members to be clear from the beginning that the purpose of an eligibility threshold is to determine the point at which an individual will have an enforceable right to support from the local authority and consequently to determine the point at which the local authority will have a legal duty to provide, or arrange the provision of, care and support to the individual. The eligibility framework must stipulate what needs for care and support will trigger that enforceable right and duty on local authorities across Wales.

At a minimum I expect that the framework will ensure that people who need help with tasks such as getting out of bed, dressing, eating, washing and bathing will be eligible for the support they need from local authority social services.

I also want you to take into account the significant impact that the breakdown of a critical relationship can have on people's well-being and their ability to maintain control over their day to day lives.

The regulations must be sensitive to, and reflect the differing characteristics for children, adults and carers. They must enable care professionals to focus on the person's needs for care and support, the impact of those needs on their well-being, and the level of risk to the individuals if those needs are not met.

The framework should also reflect the requirement in the Bill that local authorities must meet the needs of people who need to be protected from abuse or neglect, or the risk of abuse and neglect; and in addition to protect children from harm or the risk of harm. This should take place whether or not the person's care and support needs are determined as eligible needs.

I have set you a challenging task with an equally challenging timetable. I will present the new eligibility framework for public consultation in the spring and following that consultation, bring regulations and a code of practice to the National Assembly.

I wish you success in your deliberations and look forward to hearing your recommendations early in the spring.

Yours Sincerely



Gwenda Thomas AC / AM
Y Dirprwy Weinidog Gwasanaethau Cymdeithasol
Deputy Minister for Social Services

Yr Adran Iechyd a Gwasanaethau Cymdeithasol
Department for Health and Social Services



Llywodraeth Cymru
 Welsh Government

Social Services Eligibility Technical Group

Name	Role / Organisation
David Street	Corporate Director Social Services, Caerphilly CBC
Stewart Greenwell	Strategic Development Specialist, ADSS Cymru
Carys Lord	Head of Business Management and Innovation, Vale of Glamorgan CC
Jackie Davies	Service Manager Finance & Commissioning, Blaenau Gwent
Sue Darnbrook	Head of Adult Services, Ceredigion CC
Colin Turner	Head of Service Safeguarding and Family, Bridgend CBC
Julie Thomas	Programme Director NCN Development and Integration/ Director Complex Care, Aneurin Bevan UHB
Rhian Davies (Paul Swann)	Chair Disability Wales Reference Group and Director of Disability Wales
Ceri Jackson	Vice chair of Age Alliance Wales and Director of RNIB
Keith Bowen (Beth Evans)	Chair of Carers Alliance and Director of Carers Wales
Steve Harris	Director of Dewis CIL and member of the Wales Alliance for Citizen Directed Care
Amy Clifton	Age Cymru
Yvonne Rodgers	Barnardo's Cymru
Brigitte Gater	Action for Children
Chris Davies	Social Services Improvement Agency
Andrea Gray	Mental Health & Vulnerable Groups (Welsh Government)
Ann Noyes	Adult and Children's Health Policy (Welsh Government)
Chris Humphrey	Strategy Inspector, CSSIW (Welsh Government)
David Clayton	Delivering Policy for Children and Adults (Welsh Government)
Huw Maguire	Family Support (Welsh Government)
Lynda Chandler	Integration Policy and Delivery (Welsh Government)
Martin Semple	Office of the Chief Nursing Officer (Welsh Government)
Rachel Brown	Primary and Community Care Policy (Welsh Government)
Stephen Gear	Safeguarding Team (Welsh Government)

Facilitator

Professor Keith Moultrie, Institute of Public Care, Oxford Brookes University

Policy Team

Lee Davis, SS Assessment and Care Planning (Welsh Government)

Heather Giles, SS Assessment and Care Planning (Welsh Government)

Deputy Director

Margaret Provis, SS Leadership and Improvement (Welsh Government)

Yr Adran Iechyd a Gwasanaethau Cymdeithasol
Department for Health and Social Services



**Grŵp Technegol Gwasanaethau Cymdeithasol ar
Gymwysedd**

Llywodraeth Cymru
Welsh Government

Enw	Rôl / Sefydliad
David Street	Cyfarwyddwyr Corfforaethol Gwasanaethau Cymdeithasol Cyngor Bwrdeistref Sirol Caerffili
Stewart Greenwell	Arbenigwr Datblygu Strategol Cymdeithas Cyfarwyddwyr Gwasanaethau Cymdeithasol Cymru
Carys Lord	Pennaeth Rheoli Busnes ac Arloesi, Cyngor Sir Bro Morgannwg
Jackie Davies	Rheolwr Gwasanaethau Cyllid a Chomisiynu, Blaenau Gwent
Sue Darnbrook	Pennaeth Gwasanaethau Oedolion, Cyngor Sir Ceredigion
Colin Turner	Pennaeth Diogelu Gwasanaethau a'r Teulu, Cyngor Bwrdeistref Sirol Pen-y-bont ar Ogwr
Julie Thomas	Cyfarwyddwr Rhaglenni Datblygu ac Integreiddio NCN/ Cyfarwyddwr Gofal Cymhleth, Bwrdd Iechyd Prifysgol Aneurin Bevan
Rhian Davies (<i>Paul Swann</i>)	Cadeirydd Grŵp Cyfeirio Anabledd Cymru a Chyfarwyddwr Anabledd Cymru Wales
Ceri Jackson	Is-gadeirydd Cynghrair Henoed Cymru a Chyfarwyddwr RNIB
Keith Bowen (<i>Beth Evans</i>)	Cadeirydd Cynghrair y Gofalwyr a Chyfarwyddwr Cynhalwyr Cymru
Steve Harris	Cyfarwyddwr Dewis CIL ac aelod o Cynghrair Cymru ar gyfer Gofal a Gyfarwyddir gan Ddinasyddion
Amy Clifton	Age Cymru
Yvonne Rodgers	Barnardo's Cymru
Brigitte Gater	Gweithredu dros Blant
Chris Davies	Asiantaeth Gwella Gwasanaethau Cymdeithasol
Andrea Gray	Iechyd Meddwl a Grwpiau Agored i Niwed (Llywodraeth Cymru)
Ann Noyes	Polisi Iechyd Oedolion a Phlant (Llywodraeth Cymru)
Chris Humphrey	Arolygydd Strategaeth AGGCC (Llywodraeth Cymru)
David Clayton	Cyflawni Polisi i Blant ac Oedolion (Llywodraeth Cymru)
Huw Maguire	Cymorth i Deuluoedd (Llywodraeth Cymru)
Lynda Chandler	Polisi a Chyflawni Integreiddio (Llywodraeth Cymru)
Martin Semple	Swyddfa'r Prif Swyddog Nyrsio (Llywodraeth Cymru)
Rachel Brown	Polisi Iechyd Oedolion a Phlant (Llywodraeth Cymru)
Stephen Gear	Y Tîm Diogelu (Llywodraeth Cymru)

Hwylusydd

Yr Athro Keith Moultrie, y Sefydliad Gofal Cyhoeddus, Prifysgol Oxford Brookes

Tîm Polisi

Lee Davis, Asesu a Chynllunio Gofal Gwasanaethau Cymdeithasol (Llywodraeth Cymru)

Heather Giles, Asesu a Chynllunio Gofal Gwasanaethau Cymdeithasol (Llywodraeth Cymru)

Dirprwy Gyfarwyddwr

Margaret Provis, Arwain a Gwella Gwasanaethau Cymdeithasol (Llywodraeth Cymru)

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Health and Social Care Committee Inquiry into the availability of Bariatric Services – Evidence from the Welsh Government

Introduction

1. This paper provides information for the Health and Social Care Committee's inquiry into the availability of bariatric services in Wales. The paper addresses the issues the committee will be considering.
2. Bariatric surgery is a specialised service, and the Welsh Health Specialist Services Committee (WHSSC), is responsible for the planning and delivery of specialised and tertiary services in Wales on behalf of Local Health Boards. WHSSC decides how the monies allocated to this service are spent and the criteria to be met if an individual is to qualify for surgery.
3. The current access criteria, which have been in place in Wales since 2009, were developed to focus the scarce resource available for bariatric surgery on those patients with the greatest ability to benefit from surgery. WHSSC set criteria so that surgery (either gastric band or gastric by-pass), is funded only when a patient meets specific clinical criteria, including having a BMI of more than 50, and serious co-morbidities.
4. Clinical assessment and suitability for surgery is undertaken for all Welsh patients by a Multi-Disciplinary Team Panel at the Welsh Institute of Metabolic and Obesity Surgery (WIMOS). This assessment includes physical and psychological considerations, as well as the requirement that weight loss goals and lifestyle changes are agreed before surgery is considered. The panel considers paper evidence so that patients are not required to travel to the Institute for the assessment.

Progress made by Local Health Boards on the recommendations highlighted within the Welsh Health Specialised Services Committee Review of Bariatric Surgery Provision and Access Criteria in the Context of the All Wales Obesity Pathway report

5. In 2012, WHSSC undertook a review of bariatric surgery policy. The review assessed the impact of health outcomes and costs to NHS Wales of adopting the National Institute for Health and Clinical Excellence (NICE) guidance for bariatric surgery. The aim of the review was to recommend options to the WHSSC Joint Committee for revision of the current bariatric surgery policy.
6. The WHSSC review report, published in December 2012, recommended that the number of procedures and the amount of funding be increased, from 80 procedures and £0.75m of investment in 2011/12, as follows:

	2013/14	2014/15	2015/16	2016/17	2017/18
Cases (all Wales)	128	171	214	257	300
Rate (per100,000 pop)	4.3	5.7	7.1	8.6	10
Spend	£0.96m	£1.29m	£1.61m	£1.93m	£2.21m
S. Wales	£0.66m	£0.88m	£1.1m	£1.32m	£1.5m
N. Wales	£0.30m	£0.41m	£0.51m	£0.61m	£0.712m

7. WHSSC also recommended that the access criteria be reviewed.
8. The WHSSC review recommended a dual approach of improvement in the lower tiers of the obesity pathway, while at the same time investing in a phased increase in bariatric surgery.
9. The WHSSC commissioning plan for 2013/14 includes phase 1 of this additional investment which, due to lead-in time, is now expected to commence early in 2014/15. The broader investment profile to bring Wales up to the NICE commissioning guidance rate of 10 bariatric procedures per 100,000 population per annum is reflected within WHSSC's commissioning planning for 2014/15 onwards.
10. In addition, work is underway by Public Health Wales to draft the clinical access policy for a tier 3 weight management service. WHSSC is working with PHW to ensure that the referral gateway between Level 3 and Level 4 services is clear and agreed.
11. Revised access criteria, to go alongside the increase in commissioned levels of activity, are also currently being agreed and are set out in the evidence paper submitted by WHSSC. These will allow referral for consideration for bariatric surgery of patients that meet the NICE criteria. However, a range of other criteria will also be applied, including requirements for sufficient prior engagement with non-surgical services. The decision to offer surgery will be made by the bariatric surgery team at WIMOS.

The effectiveness of specialist services, within Level 3 and 4 of the All Wales Obesity Pathway, in tackling the rising numbers of overweight and obese people in Wales; and how these services are measured and evaluated, including in terms of delivering value for money

12. In 2010, the Welsh Government launched the All Wales Obesity Pathway, which sets out the approach for the prevention and treatment of obesity in Wales, from community-based prevention and early intervention, to specialist medical and surgical services. Health boards have examined policies, services and activities for both children and adults and are implementing solutions to address local

needs.

13. The Pathway describes four levels of intervention, along with the minimum service requirements for each level that LHBs should be working towards:

The first level aims to ensure the availability and promotion to the public of a range of opportunities to support individuals in achieving and maintaining a healthy body weight without the need to access specific health services, backed by the provision of a supportive environment;

Level 2 is about the provision of a range of services for individuals who wish to lose weight and have been identified as being at increased risk of obesity by a member of the primary care team;

The third level aims to ensure availability of services for obese individuals who have one or more co-morbidities and who have tried several interventions without success, or those with complex emotional relationships with food. These services provide more specialist interventions including dietary, physical activity and behavioural components than previous interventions, which can be delivered both through primary and secondary care. They act as a gateway to secondary care ensuring that secondary care services are used appropriately;

Levels 3 and 4 are specific interventions for those with established obesity and co-morbidity, and will not therefore tackle the rising numbers of overweight and obese people in Wales;

Level 4 is about providing a specialist medical and surgical service (bariatric surgery) to those individuals who have failed to achieve or maintain adequate weight loss through other interventions in the pathway.

14. Health boards have worked jointly with local authorities and other stakeholders to examine local policies, services and activity for both children and adults against the All Wales Obesity Pathway and have been implementing local solutions to address local needs.
15. Bariatric surgery has been demonstrated to be cost-effective in appropriately selected individuals. The published literature indicates that the cost-effectiveness of bariatric surgery is well within the cost-effectiveness threshold typically applied by NICE when recommending interventions for commissioning by the NHS. There is some evidence which shows that bariatric surgery can be cost saving in certain patients with a payback period of approximately 2 years (particularly early-onset diabetes that resolves following surgery).

Levels of investment currently allocated to provide bariatric surgery in Wales and the availability of obesity surgery and specialist weight management services across Wales

16. Progress made by LHBs is monitored annually. This shows that all LHBs are providing level 1 and 2 services.
17. To date the Welsh Government is aware of only one LHB which has introduced a comprehensive level 3 service, in line with NICE guidance (Aneurin Bevan Health Board). The Welsh Government will continue to monitor the situation and has met with LHBs and PHW to discuss how this gap can be filled.
18. All LHBs have access to level 4 services (bariatric surgery) which is monitored by WHSSC. Surgery for the population of south Wales is provided at WIMOS, which is based at Morriston hospital, Swansea. Surgery for north Wales residents is currently undertaken in Salford Royal NHS Trust, on the basis that travelling to Greater Manchester is less inconvenient for patients and their relatives than Swansea.
19. The Welsh Government is currently undertaking a monitoring exercise of the obesity pathway. LHBs are being asked to assess their performance against the minimum service requirements outlined in the pathway by 26 February 2014.
20. The levels of investment currently allocated within contracts for bariatric surgery are £500,000 per year for South Wales (with all relevant LHBs contributing) and approximately £250,000 per year for north Wales. This will increase in 2014/15 in line with the planned growth profile set out in the WHSSC review as set out at paragraph 6 above.

Summary

21. Obesity has a clear and persistent social gradient; we therefore need to increase the focus on deprived areas. Local communities have an important role to play in tackling this issue, and it is important that we look to communities themselves to take action to address obesity, with the government and healthcare deliverers providing appropriate help and support where we can. The Optimising Outcomes policy recently introduced by Cardiff and Vale UHB to encourage pre-surgery weight loss is a notable example of such an approach. However, the growth in demand, and the pace of development of services, means that there will always be limits on the services which can be secured at any point in time.

Witness name	Request	Response
Dr Nadim Haboubi, National Obesity Forum for Wales	Dr Haboubi agreed to provide further detail on the number of patients that he has referred for bariatric surgery, and the number of patients who have received surgery as a consequence of those referrals.	Dr Haboubi has referred 27 patients, out of these only one has had surgery, and two are awaiting surgery.
Mr Jonathan Barry, British Obesity and Metabolic Surgery Society	Mr Barry agreed to provide further information on the 11 full operating lists he cited as lost in the last financial year, including further information about what “11 full operating lists” amounts to in terms of patient numbers and as a proportion of WIMOS’s overall workload.	No response received to date.
Dr Jayne Layzell, Local Health Boards	Dr Layzell agreed to clarify whether an independent evaluation of the “Healthy Schools” programme has been undertaken.	Following the meeting, Dr Layzell received the independent evaluation of the WNHSS from a colleague. It has been more recently evaluated by Public Health Wales as part of the Health Improvement Review, in less detail, and might not be considered as independent; the outcome of that review was that the programme should continue to be funded, and be strengthened by improving the evaluation to include outcomes, incorporating the Health Behaviours in School aged Children survey questions, currently used to internationally compare children’s health behaviours.

		<p>A copy of the document can be viewed here: http://www.cardiff.ac.uk/socsi/research/publications/workingpapers/paper-138.html</p>
<p>Dr Khesh Sidhu, Welsh Health Specialised Services Committee</p>	<p>Dr Sidhu agreed to clarify NICE figures he cited during the session in relation to:</p> <ul style="list-style-type: none">- the number of individuals in Wales eligible for referral to bariatric services;- the number of individuals eligible for bariatric surgery;- the number of individuals likely to accept surgery.	<p>Dr Sidhu provided a copy of two pages extracted from the 'Review of Bariatric Surgery Provision and Access Criteria in the context of the All Wales Obesity Pathway', from which Dr Sidhu obtained the figures cited.</p> <p>A copy of the document extract is included in the pack (HSC(4)-10-14 Paper 9).</p>



GIG
CYMRU
NHS
WALES

Pwyllgor Gwasanaethau Iechyd
Arbenigol Cymru (PGIAC)
Welsh Health Specialised
Services Committee (WHSSC)

AGENDA ITEM 10

10 January 2013

MANAGEMENT OF OBESITY IN WALES

Review of Bariatric Surgery Provision and Access Criteria in the Context of the All Wales Obesity Pathway

Report of	Director of Planning
Paper prepared by	Planner for Cardiothoracic Programme
Action/Decision required	<p>It is recommended that:</p> <ol style="list-style-type: none">I. Health Boards expedite development of the obesity pathway (in particular, level 3 services) to increase provision of weight management services for their populations. This will also support any planned increases in bariatric surgery.II. Health Boards agree to an investment plan to increase the population rate of bariatric surgery from 80 cases to 300 cases (10 per 100,000 population) over 5 years (option 3).III. Health Boards agree to increase bariatric surgery activity from 80 to 128 cases in 2013/14 (as part of the schedule for investment option 3).IV. The criteria for bariatric surgery are revised with a view to broadening the criteria to take account of evidence that the benefits of surgery tend to be greater in individuals with early onset of comorbidity. Recommendations for revised criteria are reported to the Joint Committee in June 2013.

	V. Until planned volumes of bariatric surgery increase to the levels necessary to sustain a local service in line with national quality standards, referrals to bariatric surgery for patients resident in North Wales should continue to be made out of area.
Link to Board Committee (s)	
Link to Standards for Health Services in Wales	This paper links to the following Standards for Health: 5. Care Planning and Provision

1. SITUATION/INTRODUCTION

The purpose of this report is make recommendations to Health Boards on the development of the obesity pathway, on investment options to increase the provision of bariatric surgery and on revision of the bariatric surgery access criteria, in order to optimise their use of resources to address the problem of obesity.

2. BACKGROUND

Obesity is widely recognised to be a risk factor of increasing significance for ill-health and disability in Wales. Prevalence estimates derived from the Welsh Health Survey indicate high levels of obesity in Wales (over 20% of the adult population); as many as 2% (or 60,000 individuals) are estimated to be severely obese.

There is no single health service which can alone address the problem of obesity; an adequate response requires a coordinated pathway of services. This is recognised in the Welsh Government's All Wales Obesity Pathway (2010) which describes 4 levels of obesity services from primary prevention at level 1 through to specialised intervention in the form of bariatric surgery at level 4. It is also reflected in national obesity management guidance (NICE 2006) under which patients should have accessed specialist non-surgical weight loss services before referral to a bariatric surgical centre.

Agenda Item 5b

Health and Social Care Committee – inquiry into the availability of bariatric services

Working lunch with Swansea University Academics, 13 February 2014

Members present: David Rees, Elin Jones, Lindsay Whittle, Kirsty Williams, Gwyn Price, Rebecca Evans.

As part of its inquiry into the availability of bariatric services, the Health and Social Care Committee attended a working lunch with Swansea University academics on 13 February. The aim of the lunch was to allow Members the opportunity to discuss with the academics any research that they were undertaking, or aware of, that may be of relevance to the inquiry.

Following the working lunch the academics each provided a note on the research that was discussed with the Committee, as the relevance of their work could inform the Committee's report on the inquiry.

Academics in attendance:

- Dr Cathy Thornton, Reader in Immunity;
- Dr Sarah Prior, Lecturer in Diabetes;
- Dr Richard Bracken, Associate Professor in Exercise and Biochemistry;
- Dr Danielle Jones, Post doc Researcher in Diabetes.

Dr Cathy Thornton PhD

Obesity in pregnancy is associated with adverse maternal and fetal outcomes with an allied burden on health care resources. Long term health consequences for the offspring include: hypertension/cardiovascular disease, insulin resistance/type 2 diabetes, and obesity. Fetal programming of metabolic function likely underlies these relationships: high maternal levels of glucose, free fatty acids and amino acids underlie permanent changes in appetite control, neuroendocrine function, and energy metabolism. The pathophysiological mechanisms linking maternal obesity with adverse outcomes in the offspring are unknown but could include changes in metabolism of glucose and lipids, adipose-derived mediators such as adipokines, and inflammation. We are studying the effects of maternal obesity on the inflammatory response of the placenta and newborn (using umbilical cord blood). This will help us to better understand the relationship between the inflammatory response of mother and child, provide information for improving pre-conception education of women, and identify strategies to limit the detrimental effect of maternal obesity on the health of their children.

Dr Sarah Prior

‘Does bariatric surgery adversely impact on diabetic retinopathy in persons with morbid obesity and type 2 diabetes?’ - a pilot study

(Authors: RL Thomas, SL Prior, JD Barry, SD Luzio, N Eyre, S Caplin, JW Stephens, DR Owens).

We conducted a retrospective pilot analysis of electronic hospital records between 1998 and 2012 to assess the incidence and progression of diabetic retinopathy (DR) 12 months post bariatric surgery in persons with morbid obesity and type 2 diabetes.

40 out of 148 patients had pre- and post-surgery DR screening. Of those without DR pre-surgery 1.5% (n=26) progressed to minimum background DR (BDR) post surgery. Those with minimum BDR pre-surgery (n=9) revealed no progression, with 55.6% (n=5) showing evidence of regression. One person with moderately severe BDR and two with pre-proliferative DR (PPDR) prior to surgery experienced progression. Two persons with PPDR prior to surgery remained under the hospital eye services and were therefore not eligible to be re-assessed by the screening service.

There was a low incidence of new DR and progression of DR in those either without evidence of retinopathy or with minimal BDR prior to surgery with some subjects showing evidence of regression. There was however a risk of progression of DR in those with moderate BDR or worse, and should therefore be monitored closely post-surgery.

In our study those persons who experienced progression of DR had pre-existing moderate DR, higher fasting plasma glucose levels and higher systolic blood pressure prior to surgery. Additionally they demonstrated a greater reduction of fasting glucose post-surgery compared to those with no change or regression of DR. Therefore, persons with these characteristics pre-operatively should be monitored closely post-surgery for evidence of progression. Attempts should also be made to optimise therapy in those with high glucose and blood pressure prior to surgery. Larger prospective studies are now required to better assess the influence of the normalisation of glycaemic control after bariatric surgery on microvascular outcomes such as DR, nephropathy and neuropathy.

(Bibliography: J. Diabetes Complicat. 2014 28(2): 191-195)

Dr Richard Bracken

Thank you to the Chair for the opportunity to contribute to the inquiry into availability of bariatric services. As an exercise physiologist, my research interest is in the exploration of the physiological, metabolic and functional benefits of being more physically able in individuals who are obese and/or have diabetes (type 1 or 2). Over my research career, I have witnessed enormous positive benefits in individuals who were confident to start and maintain a regular physical activity programme; often through our funded research studies.

It was encouraging that at several points in the meeting mention was made of the need for a 'joined-up' approach of surgeons, physicians, psychologists and dieticians to deal with the obese individual before or after bariatric surgery. In my view, it is essential that an exercise physiologist is also part of the 'care programme' where the functional capacity of the individual is established, improved and maintained following surgery.

The World Health Organisation now ranks physical inactivity as the fourth biggest killer ahead of obesity and is the main cause for ~21–25% of breast and colon cancers, 27% of diabetes and 30% of ischaemic heart disease. Being more physically active reduces post-surgical complications arising from a continued sedentary lifestyle and contributes to better weight management of the individual post-bariatric surgery.

Recommendation: Inclusion of an exercise physiologist that strengthens the effectiveness of a multidisciplinary care team.

Dr Danielle Jones

Oxidative stress is an imbalance between the production of free radicals and the ability of the body to detoxify their harmful effects by antioxidants. A free radical is an oxygen containing molecule that is highly reactive with other molecules. Oxidative stress leads to many conditions including neurodegenerative diseases such as Parkinson's disease and Alzheimer's disease, gene mutations and cancers, chronic fatigue syndrome, heart and blood vessel disorders, atherosclerosis, heart failure, heart attack and inflammatory diseases.

The overall aim of this thesis was to investigate the role of fat in obesity and type 2 diabetes (T2DM) focusing on markers of oxidative stress and gene expression (the increased or decreased activation of particular genes) in human abdominal fat from subjects categorised as lean (L), obese (O) and obese with type 2 diabetes (ODM). It was expected that oxidative stress levels would increase with obesity and T2DM. However, results showed lower level of oxidative stress in subjects with obesity and type 2 diabetes. Overall, there appeared to be a protective mechanism in the subjects with diabetes. A significant proportion of the subjects with diabetes were on drug therapies which may have affected the results in these experiments as they may minimise the effects of oxidative stress.

Expression of genes, which may code for proteins involved in oxidative stress and antioxidant production, were looked at in the fat to identify any differences in obesity and diabetes. An increased expression of an antioxidant gene (Glutathione reductase) was seen in subjects with obesity and diabetes compared to those without. From this it was concluded that an environment of high oxidative stress, which may be caused by increased blood glucose in diabetes, causes increased expression of this antioxidant gene.

From these results, it may be hypothesised that within these subjects, the situation of oxidative stress is in fact reversible as the antioxidant capacity in these subjects is evident, and in combination with correct drug therapy it may be possible to combat oxidative burden and reduce the subsequent damage inflicted upon the cells. Particularly within the obese and obese with type 2 diabetes subjects in this study, bariatric surgery may play a positive role in the correction of this oxidative state and it would be of interest to be able to follow up this study by repeating this analysis one year post-operative to see if oxidative burden has improved in these subjects.

Agenda Item 5c

Health and Social Care Committee – inquiry into the availability of bariatric services

Visit to the Welsh Institute of Metabolic and Obesity Surgery, Morriston Hospital, 13 February 2014

Members present: David Rees, Elin Jones, Lindsay Whittle, Kirsty Williams, Gwyn Price, Rebecca Evans.

As part of the inquiry into the availability of bariatric services, the Health and Social Care Committee visited the Welsh Institute of Metabolic and Obesity Surgery (WIMOS), Morriston Hospital on 13 February 2014. The aim of the visit was to learn more about the service provided by Wales's only NHS bariatric surgery unit.

The Committee met informally with members of WIMOS's multidisciplinary team, including the Institute's resident surgeons, physician, anaesthetist, specialist nurse, dietician, psychologist, theatre sister and surgical administrators, to discuss their work. A patient who had undergone bariatric surgery at WIMOS was also present and provided Members with an outline of her experience of bariatric services – including surgery – to date.

Welsh Institute of Metabolic and Obesity Surgery

The Welsh Institute of Metabolic and Obesity Surgery (WIMOS) at Morriston Hospital is the only provider of Level 4 bariatric surgery services in Wales. It was formed in November 2010 and undertook its first operations in January 2011.

WIMOS assesses all Welsh patients referred for Level 4 services in Wales against the criteria set by the Welsh Health Specialised Services Committee (WHSSC). In terms of undertaking surgery, WIMOS serves the south Wales population – the north Wales population is required to travel to England where services are commissioned at the Salford Royal NHS Foundation Trust. WIMOS provides a full multidisciplinary team, pre-operative assessment and follow-up service for two years following surgery and has access to two full-time consultant bariatric surgeons.

Note of Members' discussion with WIMOS's multidisciplinary team

This note outlines the themes discussed informally by Members and WIMOS's multidisciplinary team during the Committee's visit. Many of the issues discussed built on points made during the morning's formal oral evidence session during which Mr Jonathan Barry and Mr Scott Caplin – both bariatric surgeons at WIMOS – gave formal oral evidence.

Eligibility criteria and service development

The disconnect between eligibility criteria in Wales and NICE guidance was highlighted during the visit to WIMOS. It was noted that fair and equitable access to bariatric surgery in Wales will not be achieved without adhering to NICE guidance, which sets lower criteria for access to surgery than that currently in place within the Welsh system.

WIMOS staff explained that the DUBASCO tool is used to identify those eligible for surgery in Wales. This is purely a rationing tool used to satisfy the requirement to operate on the specified number of patients commissioned by WHSSC each year – this figure was 67 patients (out of a potential caseload approximated at 3000) in the last year. It was noted that WHSSC is looking to commission an increased number of bariatric surgery procedures in future years. WIMOS staff noted, however, that there has been “inertia” with progress in this area.

It was noted at the time of the visit that the number of procedures that would be commissioned by WHSSC for the 2014–15 financial year were yet to be confirmed, but that an increase from 67 to 120 had been discussed. It was noted that, with the resource of the two available surgeons being used to full effect, WIMOS could do 240 operations each year. If Wales were to become NICE compliant, it was noted that a backlog of eligible patients would arise.

Treatment for children and young people

It was noted that surgery for under-18s is not currently permitted in Wales. The importance of ensuring that all patients – whether under or over 18 – have access to Level 3 services was emphasised. Staff commented that there is a growing number of obese children and young people presenting for treatment but no specialist paediatric Level 3 service is currently available in

Wales. It was noted that WIMOS staff are often waiting for individuals to cross the line to 18 before anything useful can be done to assist them.

Allied services – dietetics, psychology etc.

The importance of the multidisciplinary approach to bariatric services was emphasised during the visit to WIMOS. The important role of the dietician and psychologist was emphasised and it was noted that patients are often referred to WIMOS having not had previous access to allied health professionals. This, in turn, can lead to inappropriate referrals to WIMOS for bariatric surgery before an individual's lifestyle choices or psychological profile has been fully explored. It was argued that more adequate provision of Level 3 services could ensure that inappropriate referrals to WIMOS were reduced.

Impact of surgery

With regard to economics, it was noted that, in terms of cost–benefit, there is a misperception that bariatric surgery is expensive. According to WIMOS staff, bariatric surgery becomes cost neutral within two and a half years of the procedure. This is due to, for example, a subsequent reduction in other illnesses (e.g. diabetes) and the reduction in the volume of medication required by the patient. Committee members were also told that employment rates in the post–bariatric surgery population are the same as in the normal population.

In terms of physical impact, WIMOS reported an 85% remission rate for patients with diabetes, significant reduction in rates of hypertension and marked improvements in incidences of sleep apnoea. Members were also told that women undergoing bariatric surgery halve their risk of developing all types of cancer.

Reference was also made to a growing body of evidence that operating on obese women before they have children can reduce co–morbidity in their offspring.

Patient experience

During the visit Members met a patient who has undergone bariatric surgery at WIMOS. The impact of her obesity included orthopaedic problems that

caused immobility and forced her to leave employment that she loved. She also suffered hypertension and depression as a result of her obesity and unemployment. She explained that her referral to WIMOS evolved via her GP and orthopaedic surgeon. The patient explained to Members that, post surgery, her life has changed dramatically. She has been able to undergo one knee replacement – this has improved her mobility, and another will follow shortly. The only remaining concern for her is the fact that she does not currently qualify for body contouring treatment on the NHS – i.e. excess skin removal – as this is considered cosmetic in her case.

Agenda Item 5d

Health and Social Care Committee – inquiry into the availability of bariatric services

Focus group event, 12 March 2014

Members present: David Rees, Elin Jones, Lynne Neagle, Lindsay Whittle, Kirsty Williams, Gwyn Price, Rebecca Evans, Janet Finch Saunders.

As part of the inquiry into the availability of bariatric services, the Health and Social Care Committee hosted a focus group event on 12 March. The aim of the focus groups was to discuss bariatric services with patients, physicians, surgeons and allied health professionals who have direct experience of these services in Wales.

Four groups comprising a mixture of committee members, patients and health professionals were given one hour to discuss the following five questions:

1. Multidisciplinary bariatric teams are made up of a variety of specialists and practitioners. What improvements, if any, could be made to patients' access to these multidisciplinary teams, and weight management clinics, in Wales?
2. Do you think current criteria identifying those who are eligible for bariatric surgery are adequate and appropriate?
3. How are patients assessed for bariatric surgery and what problems are encountered?
4. With regard to the treatment of patients with weight issues, is the level of training, information and support provided to health professionals adequate?
5. What effect does weight management intervention, or lack thereof, have on the lives of patients?

The groups were invited to share their observations on each question in a subsequent plenary session.

NOTE OF PLENARY DISCUSSION

Question 1: Access to multidisciplinary teams and weight management clinics in Wales

Fragmented implementation

There was a clear consensus across the four focus groups that access to multidisciplinary teams and weight management clinics is inadequate in Wales. Reference was made to the existence of a “post-code lottery” for Welsh patients, with only Aneurin Bevan University Health Board currently providing a Level 3 service. Although participants praised the All Wales Obesity Pathway as a good strategic document, frustrations were expressed at the fact that its implementation remains piecemeal.

Timely access to skilled and specialist multidisciplinary teams

Participants noted that access to a multidisciplinary team comprising dietetic, psychological, clinical and fitness support is crucial to ensuring sustained weight loss for bariatric patients. The importance of having access to a skilled team with expertise in lifestyle change as well as dietetic and/or clinical interventions was emphasised. Furthermore, participants noted the need for timely access to the support of multidisciplinary teams – examples of significant waits due to the lack of Level 3 services were cited. Participants highlighted that delays in accessing services often perpetuated already complex and high-risk bariatric cases. There was consensus across the groups that access to specialist multidisciplinary teams is important both before and after bariatric surgery; post-operative monitoring and care was cited as a key factor in an individual’s ability to maintain a healthy lifestyle after surgery. Participants questioned whether adequate specialist resource is available currently in Wales given how few Local Health Boards have commissioned Level 3 services.

The role of primary care

The importance of ensuring “every contact counts” was highlighted and it was suggested that further work is needed to improve general practice’s

approach to bariatric patients with many participants citing ignorance and prejudice as a barrier to accessing specialist services. Examples were given of patients having to request specialist weight management intervention as opposed to being actively offered support of this kind. In cases where general practitioners and primary care workers have a better understanding of the need for specialist bariatric intervention, it was noted that difficulties still remain with referring individuals to multidisciplinary teams due to the paucity of specialist weight management clinics. It was also noted by some participants that patients often see several general practitioners rather than the same individual – this can be unhelpful when seeking to establish which services are required.

Paediatric services

Participants emphasised that weight management issues often begin in childhood. It was highlighted, however, that weight management services are more limited for children than adults. There was consensus across the groups that specialist paediatric services ought to be provided to prevent or reduce the escalation of individuals' weight management issues in later life.

Level 1 and 2 services

Reference was made to the recently developed 'Foodwise for Life' programme, an eight week structured weight management programme designed by public health dieticians in Wales. It was noted that this programme is designed to be delivered by a range of community-based staff, and to deliver services at levels 1 and 2 of the All-Wales Obesity Pathway. Reference was made to the possible contribution of third-party services such as Weight Watchers and Slimming World. Although it was acknowledged that for complex cases a more specialist approach is required, participants noted that a partnership approach with such schemes could be beneficial in order to avoid individuals reaching the point of needing the more specialist Level 3 and 4 services.

Question 2: Eligibility criteria for bariatric surgery

The need to adhere to NICE guidance

All groups agreed that there is a pressing need to work towards adherence to existing NICE guidance on bariatric surgery. It was emphasised that this is

not currently implemented in Wales, although it is mainstreamed in England. It was noted that out of 1000 patients referred to Wales's only provider of NHS bariatric surgery, 98% have not been eligible for surgery despite meeting the criteria outlined in the NICE guidance.

BMI and other co-morbidities

There was consensus that thresholds in Wales for accessing surgery remain too high. It was noted that the need for a patient in Wales to display additional co-morbidities and a higher BMI than in England in order to qualify for surgical intervention acted as a perverse incentive to individuals seeking bariatric surgery. Participants emphasised that it appeared people had to become more ill before meeting eligibility criteria, making surgery riskier for the individual and surgeons involved. The wisdom of applying such a high BMI and co-morbidity threshold in Wales was questioned.

Access to Level 3 support

It was emphasised by most participants that Level 3 and Level 4 services cannot be separated – a clear referral pathway is needed from Level 3 to Level 4, and vice versa, otherwise neither tier will work to its full potential. The importance of ensuring that all options are explored and exhausted prior to surgical intervention was highlighted. Most groups agreed that the requirement to participate for two years in a Level 3 scheme was sensible in principle as many people succeed in losing weight without surgical intervention during this period. It was also felt that this process would help ensure that those who are in most need of surgery actually receive it. There was consensus, however, that the criteria to participate for two years in a Level 3 service is too high a threshold when such services are not available on the necessary scale in Wales.

Age limits

There was consensus across the groups that bariatric surgery should only be available to patients under 18 years of age in exceptional circumstances as patients of this age are still growing. It was acknowledged, however, that the right support is needed promptly for children and young people – including access to specialist Level 3 services – in order to address weight management problems as early as possible. Although participants advocated

the availability of specialist paediatric weight services in Wales, nobody was aware of any currently in existence here.

Question 3: Assessment for bariatric surgery

The role of Level 3 services

The important role played by Level 3 services in assessing the need for – and referring to – Level 4 services was emphasised by participants. As outlined in relation to question 2, however, the focus groups noted that the scarcity of Level 3 services in Wales impacts on the NHS's ability to assess patients individually. It was argued that this has led to an inadequate level of assessment of individuals for bariatric surgery in Wales. There was a general consensus that referral for Level 4 surgical interventions should go through Level 3 services as outlined in the All Wales Obesity Pathway, but that the problem remains that Level 3 services are not available in the necessary quantity.

Post-operative care

It was emphasised that patients need to be fully briefed about the consequences of bariatric surgery and its associated risks, and the need to engage fully with a post-operative care regime. It was noted that a failure to commit to support services following bariatric surgery can have serious physical and psychological consequences.

Impact of refusal for surgery

It was noted that individuals are not always informed of the reasons why they are refused surgery. Participants felt that, if patients are refused, they should be provided with an explanation. Guidance about what steps they can take in the future should also be available. It was noted that many of those who are refused surgery in Wales travel over the border or further afield, often seeking private treatment. Examples of patients seeking cheaper treatment overseas from unscrupulous providers were given, with reference being made to the impact this has on the NHS when individuals return and require corrective surgery and/or treatment in Wales.

Excess skin removal

The importance of considering the impact of excess skin following successful bariatric surgery was emphasised. It was noted that, although excess skin removal is currently considered a cosmetic procedure unless specific physical complications arise, the psychological impact of excess skin on patients following surgery is significant. Participants believed that excess skin removal should be considered part of the health care of people who have undergone bariatric surgery, rather than as a cosmetic procedure. There was consensus among participants that excess skin removal ought to be factored in to all assessments and costs for bariatric surgery.

Cancellation of surgery

A number of participants cited examples of bariatric surgery, even once assessed as necessary, being cancelled. It was noted that cancellations arise due to bed capacity constraints, with other health conditions such as cancer and heart disease being prioritised.

Question 4: Training, information and support for health professionals

Training and support

Participants cited examples of healthcare practitioners displaying ignorance and prejudice towards obese individuals, with many patients being told to simply exercise and improve their diet. The need to train practitioners to improve their understanding of the underlying causes of obesity and raise their awareness of specialist services was emphasised. It was noted that some health professionals lack confidence when raising weight management issues with patients, and that training in this area is required, to reduce frustration for professionals and patients. It was noted that not enough focus is placed on the importance of training for health professionals, and that some GPs in particular may not have sufficient training or time resources to deal with complex weight issues. It was recommended that training about obesity, its causes and its treatment should be mainstreamed across all disciplines.

Skills mix

The importance of ensuring the correct skills mix among health professionals was emphasised by participants. The need for specialist training in the field of dietetics, psychology, and lifestyle interventions –

including fitness – was noted. Some participants argued that there is a need to consider a different model of care to combat obesity, looking at the need to make lifestyle as well as clinical/physical changes. In this context obesity was likened to mental health conditions, where longer-term approaches and interventions – rather than diagnoses and one-off treatments – are required.

Question 5: The impact of weight management intervention, or lack thereof, on the lives of patients

Social

It was noted that successful weight management interventions can be life-changing, not only for patients, but for the whole family. Day-to-day tasks such as shopping, socialising, and travelling can all be restricted by obesity, which has a knock-on effect on an individual's quality of life. It was suggested that equality impact assessments should include consideration of the needs of those who are overweight, as they do the needs of older people, linguistic needs or religious needs.

Physical

Participants noted that weight management interventions can have a significant impact on other associated conditions including diabetes, high blood pressure, sleep apnoea, joint problems and mobility issues among many others.

Economic

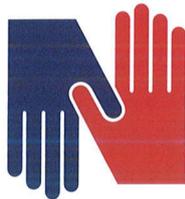
It was noted that many obese individuals may struggle to maintain a working life due to the physical and psychological impact of being overweight. The economic impact of this – both for the individual and society more widely – was emphasised. The cost-benefits of bariatric surgery were emphasised with many participants noting that successful surgery can reduce costs including other health and social care expenditure and welfare payments.

Psychological

The relatively high incidence of depression among obese people was noted during discussions. It was emphasised that psychological support is needed for patients whether or not bariatric surgery is provided – it was noted that

surgery alone might not improve a patient's perception of their own body image, particularly if excess skin is not removed.

Agenda Item 5e



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**Tina Donnelly TD, DL, CCMI, MSc
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Director, RCN Wales

27 February 2014

David Rees AM
National Assembly for Wales
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Dear David

I am writing to ask you for your support for a Committee Inquiry into community nursing.

The recent hospital reconfiguration has emphasised reducing hospital beds to enable people to be supported and cared for appropriately in their own homes. This is an aim the Royal College of Nursing wholeheartedly endorses.

This is why we are asking for the Committee to take a comprehensive overview of the situation for community nursing across Wales.

- Are there enough qualified nurses to support the patients they serve?
- What are, and should be, the relationships with social services, GPs and hospital based services?
- How do NHS community services work with independent nursing care homes, domiciliary care and third sector nursing?
- Is there sufficient development of appropriate IT support?

These are a few of the important questions we have. Attached with this letter is also a briefing on the wider issues involved.

Continued...

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Mae'r Coleg Nyrsio Brenhinol yn Goleg Brenhinol a sefydlwyd drwy Siarter Frenhinol ac Undeb Llafur Cofrestr Arbennig a sefydlwyd o dan Ddeddf Undebau Llafur a Chysylltiadau Llafur (Cydgrynhoi) 1992. The RCN is a Royal College set up by Royal Charter and a Special Register Trade Union established under the Trade Union and Labour Relations (Consolidation) Act 1992.

***Mae'r RCN yn cynrychioli nyrsys a
nyrsio, gan hyrwyddo rhagoriaeth
mewn arfer a llunio polisiau iechyd***

***The RCN represents nurses and
nursing, promotes excellence in
practice and shapes health policies***



27 February 2014

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Thank-you for your support and please do not hesitate to contact me if you would like to discuss this matter further.

Kind regards

Yours sincerely

A handwritten signature in cursive script, appearing to read 'Tina Donnelly'.

TINA DONNELLY
DIRECTOR, RCN WALES

Taking Stock: Is Community Nursing able to cope with reconfiguration?

In 2010 the Welsh Government launched the Community Nursing Strategy. In 2011 Together for Health was described as setting out “how the NHS will look in five years time, with primary and community services at the centre of delivery”.

Since then the drive to shift care from the acute hospital to the community setting has continued apace with this ambition underlying the recent reconfiguration for the NHS in Wales.

Now is an excellent time therefore to take stock of the infrastructure of community nursing service, to celebrate innovative best practice and also to identify actions needed to strengthen services.

A Committee Inquiry could achieve all of this and provide a useful investigation of the following issues:

- How community nursing can work to integrate health and social care services
- The need to model safe and quality staffing measures
- The need to prepare the future workforce (including those transferring from an acute hospital environment)
- The need for basic workforce and information
- Assessing the impact of hospital reconfiguration on community nursing
- The role and contribution of the third sector
- The need for investment in children’s community nursing.
- ICT infrastructure
- The 24 nature of care and whether services can respond.
- The connection to palliative care services

Who might be interested in providing evidence to such an Inquiry?

- Professional Organisations (such as Royal College of GPs)
- Patient & Campaigning Groups (e.g. Age Concern, Diabetes Cymru)
- Community Health Councils
- Voluntary Organisations (e.g. Womens Institute)
- Health Boards
- Local Government (or organisations such ADSS)
- Trade Unions (e.g BMA)

Community Nursing: An introduction to the issues

Registered nurses working in the community can have many different job titles. For example they could be working in a care home, in a GP surgery, as part of a community team or as outreach staff from hospitals. They could be specifically qualified as a learning disability nurse, a school nurse or a Health Visitor (Specialist Community Public Health Nurse).

The work of nurses in the community encompasses the promotion of health, healing, growth and development, as well as the prevention and treatment of disease, illness, injury and disability. Community-based nurses, and the health care assistants who work with them, enable people to achieve, maintain or recover independence where possible, and minimise distress and promote quality of life where it is not.

Community Nurses:

- support families with the joys and stresses of a new baby;
- teach school children how to manage their asthma or diabetes and develop healthy lifestyles;
- enable adults with learning disabilities to live independently;
- assess and treat patients at local GP surgeries;
- provide clinical care and rehabilitation to people at home after an operation;
- help individuals with depression on the road to recovery;
- support people with health needs in the workplace;
- assist older people with a long term condition to remain independent;
- give dignified care to those who wish to die at home or in a hospice.

The list could go on. Few of us have not had reason to rely on a community nurse.

Nurses in the community are committed to meet the coming challenges but, historically, they have simply not benefited from the national vision and investment needed to provide us with the workforce we need today. Across the UK 27 per cent of NHS community nurses are over 50 and will have retired within the next 10 years.

We are simply not educating enough new staff to fill these posts, let alone increase services.

The RCN believes strongly that a renewed investment in the community nursing workforce is essential to support the reconfiguration process of the NHS in Wales. If the nation fails to invest in community nursing, the demand for acute health care is likely to increase.

District Nursing (DN): Special Concerns

District nurses across Wales report concerns and uncertainty about their current and future role. Without a renewed focus on the DN service across Wales, it is feared that a generalist nursing resource universally relied upon to support patients in homes and communities is in danger of disappearing.

A useful defining description of district nursing can be found in The Queen's Nursing Institute (QNI) report (2009) which asserts that *"nursing in the home is fundamentally different to nursing in clinical-type settings, in hospital or in primary care, and district nurses are specifically qualified to do it. District nursing work remains both preventive and supportive. It can also be highly technical, risk-taking, intensive and practical. The nature of the work is unpredictable and changeable; it requires district nurses to be responsive, flexible and adaptable."* The report describes the core values of the DN service as

- keeping people at home where they want to be;
- the relationship between nurse and patient as the prime therapeutic tool;
- the need to work with the whole family and their carers as a unit;
- the importance of expert assessment and care, both clinical and social; and
- the need to promote coping and independence, both practical and psychological."

District nurses could be considered the glue holding together the community nursing workforce – "specialists at being generalists" – jack of all trades in terms of clinical care, networks across health and social services – unique and necessary for untangling complexity and keeping patients safely at home

Appendix A - Community Nursing Numbers

WAG Commissioning of Community Nursing Post-registration Training Places
Statistics sourced from NLIAH

	2007	2008	2009	2010	2011-12
District Nurses	45	28	26	30	26-30
DN (modules)		98	40	40	50-107
Health Visitors	36	36	46	36	36-45
Community Psychiatric Nursing	13	21	21	21	20-33
CPNs (modules)		20	20	20	20-34
Community Learning Disability Nursing	3	2	3	2	0
CLDNs (modules)		4	6	10	4
School Nurse	22	24	24	24	22-34
School Nurse (modules)					25
Practice Nurses	20	16	18	16	16-37
PN (modules)		16	16	16	12

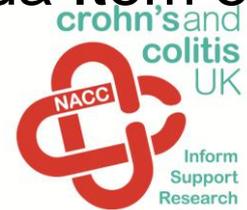
No. of District Nurses Sources from Stats Wales and presented to nearest whole number

	2007	2008	2009	2010	2011	2012
Number of District Nurses	1141	943	863	926	945	900
WTE District Nurses	755	836	745	806	823	780

NHS Nursing by area

Statistics sourced from Stats Wales and presented to nearest whole number. These figures are not for registered nurses only but include Healthcare Support Workers

	2007	2008	2009	2010	2011	2012
Acute, Elderly & General	32,831	18,591	18,651	18,726	18,531	18,560
WTE Acute, Elderly & General	16,392	16,134	16,048	16,072	15,908	15,950
No. of Community Psychiatry	1,128	1,086	1,261	1,220	1,326	1,414
WTE Community Psychiatry	968	1,012	1,168	1,130	1,232	1,312
Community Learning Disability	385	338	321	333	314	313
WTE Community Learning Disability	334	307	295	308	290	290
Community Services	4,850	3,849	4,240	4,292	4,347	4,411
WTE Community Services	3,116	3,156	3,336	3,413	3,485	3,548
School Nursing	167	162	184	256	298	309
WTE School Nursing	99	113	128	174	211	221
Neonatal	N/A	N/A	N/A	N/A	488	482
WTE neonatal	N/A	N/A	N/A	N/A	414	410



14th February 2014

Mr David Rees AM
Health and Social Care Committee Chair
National Assembly for Wales
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Dear Mr Rees,

Short Inquiry into implementation of national guidance on Inflammatory Bowel Diseases (IBD)

I am writing on behalf of Crohn's and Colitis UK to ask that you and the Health and Social Care Committee consider our proposal for a short inquiry into the implementation of national guidance for Inflammatory Bowel Disease. This replaces the draft, proposed scope for a 'short inquiry into the implementation of national guidance for luminal G.I conditions' that the Committee recently received.

Having had further discussions with colleagues in other patient organisations covered by the original draft proposed scope, we feel that it would be beneficial to narrow the inquiry's proposed scope a little, so that it focuses on IBD exclusively.

We feel that the best case for this inquiry can be made by focusing on IBD specifically, as the issues around inconsistent provision of care are well supported by the three existing rounds of the UK IBD Audit data, with a fourth which will be published in the coming months. However, this same level of data is not readily available for Coeliac Disease nor Irritable Bowel Syndrome.

Crohn's Disease and Ulcerative Colitis (two common gastroenterological conditions, known collectively as Inflammatory Bowel Disease - IBD) impact around 15,500 people in Wales. The symptoms include frequent diarrhoea (sometimes with blood and mucus in cases of IBD), acute abdominal pain, weight loss, and profound fatigue.

IBD can cause blockages in the intestine or ruptures in the lining of the intestinal wall, which require emergency surgical intervention if the condition goes untreated, or in cases of severe disease. Between 50% and 70% of patients with Crohn's Disease will undergo surgery within a lifetime. In Ulcerative Colitis lifetime surgery rates are about 20-30%. There is also an established link between IBD, particularly extensive Ulcerative Colitis, and an increased risk of developing colorectal cancer.

Standards of treatment and care for people with IBD in Wales have improved in recent years. However, they still fall behind the average for the rest of the UK. National guidance was issued in 2009 in the form of the UK IBD Standards – a collaboration between professional organisations and patient groups that sought to define good quality IBD care. In subsequent years, the Standards have been supplemented with NICE Clinical Guidelines for both Crohn's and Colitis.



David Barker, Chief Executive Keith Stewart, Chairman
Crohn's and Colitis UK is the working name for
The National Association for Colitis and Crohn's Disease
Charity registered in England No. 117148 and in Scotland No. SC038632
A company limited by guarantee in England. Company number: 5973370



Despite this, three rounds of independent UK IBD Audit data have demonstrated that basic standards of care are not being met by many Welsh hospitals, notwithstanding the former Health Minister's acknowledgement that Health Boards are 'expected to take into account the Standards'.

Given the disparity in standards of IBD care in the four UK countries, despite national guidelines, Crohn's and Colitis UK believes a short inquiry into the implementation of this guidance is now necessary. Such an inquiry could enable better understanding of the barriers to improved care for people with IBD and help address some of these barriers ahead of the publication of NICE's IBD Quality Standards in September 2014.

If you require further information, I am contactable via Policy and Public Affairs Officer Philip Reynolds at 'philip.reynolds@crohnsandcolitis.org.uk'.

Yours sincerely,

A handwritten signature in blue ink, appearing to read 'D. Barker', with a long horizontal flourish underneath.

David Barker,
Chief Executive
Crohn's and Colitis UK

Health and Social Care Committee

Proposed Scope: Inquiry into implementation of national guidance on Inflammatory Bowel Diseases (IBD)

February 2014

Terminology

Gastroenterology – A specialism that examines the whole of the gut, ranging from the oesophagus to the colon and to various other organs, including the liver, pancreas and gall bladder¹.

Inflammatory Bowel Diseases (IBD) – These are chronic, autoimmune conditions in which intestines become swollen, ulcerated and inflamed. The most common variants are Crohn’s Disease and Ulcerative Colitis.

Prevalence and patient numbers

At least 261,000 people in the UK have Ulcerative Colitis or Crohn’s Disease, with more than one in 200 people affected by IBD. Exact prevalence figures in Wales are unavailable, however, it is estimated that just over 15,500 people have the conditions, based on recent Welsh population figures².

Impact on quality of life

IBD symptoms include acute abdominal pain, weight loss, diarrhoea (sometimes with blood and mucus), tenesmus (constant urge to have a bowel movement), and severe fatigue. Symptoms vary in severity from person to person and from time to time and relapses often occur suddenly and unpredictably.

In addition to physical symptoms, the psychological impact of IBD frequently presents a significant barrier to people actively participating in work and social life. Research conducted by Crohn’s and Colitis UK revealed that the fear of experiencing an episode of incontinence is as debilitating as the actual event.

A person with Crohn’s and Colitis UK explains: *“I don’t go through the door because of that ‘fear factor’ – I won’t have an accident outside the house as I don’t go out. I visit my mum’s once a week and my husband drives me, and I shop at night because there are fewer people around.”*

Another explained that *“being faecally incontinent is completely socially unacceptable. It is more acceptable to be sick in public. Therefore the fear of being faecally incontinent has a great impact on your life.”*

¹ Royal College of Physicians, *Gastroenterology* <http://www.rcplondon.ac.uk/specialty/gastroenterology>

² ONS, <http://www.ons.gov.uk/ons/rel/pop-estimate/population-estimates-for-england-and-wales/mid-2012/mid-2012-population-estimates-for-england-and-wales.html>

Treatment options

Medical management of IBD use a hierarchy of drugs to treat acute episodes and maintain patients in remission or with a reduced level of symptoms. These are corticosteroids, aminosalicylates (5ASA), immunosuppressives (azathioprine, 6-mercaptopurine, cyclosporine) and biologics (infliximab/adalimumab).

If left untreated, or in cases of severe disease, IBD can cause blockages in the intestine or ruptures in the lining of the intestinal wall, which require emergency surgical intervention. Surgical options include resections to remove diseased sections of the gut or the total removal of the large bowel and its replacement with a stoma bag. It is also known that between 50% and 70% of patients with Crohn's Disease will undergo surgery within five years of diagnosis. In Ulcerative Colitis, lifetime surgery rates are about 20-30%.

A high proportion of IBD patients will experience one or more associated inflammatory conditions requiring care from a different specialty – osteoarthritis and inflammation of the eyes or skin are the most common additional conditions. There is also an established link between IBD, particularly extensive Ulcerative Colitis, and an increased risk of developing colorectal cancer.

Guidance

Standards for the healthcare of people who have inflammatory bowel disease. IBD Standards 2013 update. The IBD Standards Group: Association of Coloproctology of Great Britain and Ireland, British Dietetic Association, British Society of Gastroenterology, British Society of Paediatric Gastroenterology, Hepatology and Nutrition, Crohn's and Colitis UK, Primary Care Society for Gastroenterology, Royal College of Nursing, UK Clinical Pharmacy Association, Royal College of Physicians, Royal Pharmaceutical Society
Published October 2013.

British Society of Gastroenterology Commissioning evidence-based care for Patients with Gastrointestinal and Liver Disease
Published June 2012

NICE Guidance

Clinical guidelines

NICE Clinical Guideline CG118 Colonoscopic surveillance for prevention of colorectal cancer in people with ulcerative colitis, Crohn's disease or adenomas.
Published March 2011

NICE Clinical Guideline CG152 Crohn's disease
Published October 2012

NICE Clinical Guideline CG166 Ulcerative colitis
Published June 2013

Quality Standards

NICE Quality Standard Inflammatory bowel disease (to cover Ulcerative colitis and Crohn's disease)

Expected publication date September 2014

Clinical Pathways

NICE Clinical Pathway: Colonoscopic surveillance

Current status

According to WAQ60597, 'The IBD standards were issued to the NHS in February 2010 under cover of a Ministerial Letter (EH/ML/009/10). Health Boards are expected to take into account the Standards for improving IBD services and to use them to inform planning, funding and the delivery of services for IBD within their local areas.'

Although standards of treatment and care for people with Crohn's Disease and Ulcerative Colitis in Wales have improved in recent years, they still fall behind the average for the rest of the UK.

After analysing data from the 2010 UK IBD Audit (the most recent round available) it is clear that basic standards of care are not being met by many Welsh hospitals, despite the former Health Minister's acknowledgement that Health boards are 'expected to take into account the Standards'. This presents a clear contrast with other UK countries.

UK IBD Audit organisational data comparison between UK countries –

2010 Key indicator results for England, Northern Ireland, Scotland & Wales					
IBD Standard	UK Average meeting the standard	England (162 hospitals)	Northern Ireland (11 hospitals)	Scotland (13 hospitals)	Wales (15 hospitals)
Does the IBD Service have a named clinical lead?	76%	80% (129)	45% (5)	69% (9)	67% (10)
Sites with guidelines for the management of Acute Severe Colitis	79%	82% (133)	55% (6)	85% (11)	60% (9)
Sites that hold parallel gastroenterology/colorectal surgery clinics (where IBD patients are seen)	56%	47% (76)	18% (2)	62% (8)	33% (5)

A separate inpatient audit examined the experiences of people with IBD who were admitted to hospitals across the UK. Data reveals that hospitals are failing to weigh patients on admission to hospital, not prescribing blood thinning medication and specialists were not meeting regularly to discuss patients.

IBD Standards	Patients across Welsh hospitals entered into Audit receiving this care	UK average
Standard A10 – Patients admitted with known or suspected IBD should be discussed with and normally transferred to the care of a Consultant Gastroenterologist and or Colorectal Surgeon	65% of Ulcerative Colitis patients seen by specialist (108/165 patients entered into inpatient Audit from the 15 hospitals)	88% of Ulcerative Colitis patients were seen by a specialist
	50% of Crohn’s Disease patients were seen by a specialist (94/185 patients entered into inpatient audits from the 15 hospitals)	78% of Crohn’s Disease patients were seen by a specialist
Standard A10 - All IBD patients admitted should be weighed and their nutritional needs assessed	35% of Crohn’s patients were weighed (66 of 185)	72% of Crohn’s Disease patients were weighed during first admission

Suggested Terms of Reference

To examine the awareness and implementation of current national guidance for Inflammatory Bowel Diseases, especially the measures developed to support and monitor the uptake and effectiveness of such guidance.

The Committee will particularly consider the ongoing impact of guidance on improving standards of care for people in Wales to a level equivalent to that of England.

Suggested witnesses

Crohn’s and Colitis UK

Welsh Association for Gastroenterology and Endoscopy

The UK IBD Standards Group

Suggested sources of information

StatsWales

UK IBD Audit third round reports

UK IBD Audit fourth round reports (available summer 2014)